DEFINING THE BIOCITIZEN IN PLURALISTIC HEALTHCARE SETTINGS: THE ROLE OF PATIENT CHOICE

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This dissertation examines how ontologies of "personhood" are introduced and reinvented by members of healthcare systems, and how the choices of patients who opt out of public healthcare are informed by a nonconventional view of personhood in Florianópolis, Brazil. I argue that the Democratization of the Brazilian healthcare system in 1988, created a conventional vision of the "New Brazilian (bio)Citizen" that has been institutionalized by the public healthcare system and reimagined or resisted by patients who seek care outside of the system. Rather than adopting the ontology of the New Brazilian (bio)Citizen as codified in the 1988 constitution, patients have built in additional ideas about the relationship between health, the self and their rights and responsibilities as citizens of Brazil and members of humanity. As such, they can be thought of as nonconventional biocitizens who illustrate their "alternative" personhood in the choices they make as patients.

Based on twelve months of ethnographic research with an Anthroposophic Clinic and seven public health posts in Florianópolis, Brazil, and work with the Secretary of Health's Commission on Integrative Health Practices, I describe how patients who mix services or opt out of quality free public healthcare entirely, are making choices that are influenced by a vision of personhood that contrasts the "New Brazilian (bio)Citizen." I argue nonconventional biocitizens reject the biomedical personhood underpinning public healthcare, but often do not reject biomedicine itself. Nonconventional biocitizens position themselves differently in relationship to

healthcare providers, and express different positions on health and the rights and responsibilities of patients and physicians compared to conventional biocitizens. These differences are important to understanding patients' choice of provider and/or treatment.

Finally, I examine the implications for incorporating personhood in considerations of patient choice. While patients who opt out of biomedical care are often cast as noncompliant, their resistance to conventional care can be viewed as a strategy to execute the responsibilities and rights that align with their understandings of their own membership as nonconventional biocitizens. Understanding how and why individuals choose providers and treatments offers a wider picture of what patients expect, need and search for in healthcare services.

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0.0 DEDICATION

To all of my teachers in all of their shapes and forms that have guided me along the way.

1.0 PREFACE

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2.0 INTRODUCTION

2.1 STATEMENT OF THE PROBLEM: BRAZILIAN CITIZENSHIP AND HEALTHCARE CHOICE

In 1988, Brazil institutionalized a national healthcare system that made access to health a fundamental right of all Brazilian citizens. Healthcare reform was a means of demarcating the end of the military dictatorship and a return to democracy. The right to healthcare access was as much of an important milestone in shaping the country's narrative about itself as it was in revolutionizing the relationship between citizens and the State. Much like the role healthcare played in legitimizing and solidifying the new regime in Cuba and the "new man," by providing universal access to biomedical care, the Brazilian government was able to model its new relationship with the citizenry. The Brazilian government was also able to socialize the creation of the "new Brazilian citizen" through its *Sistema Único de Saúde* (SUS) (Brazil's Unified Healthcare System) and a new ontology of personhood (Brotherton 2012). The rights and responsibilities of citizenship are embodied not only in Brazil's 1988 constitution and it mandate for care. These rights and responsibilities are also encapsulated in Brazil's SUS and produced and reproduced in the numerous hospitals and health posts across the country.

Brazil has continued to struggle in providing universal access to quality healthcare across the nation but has made considerable gains in expanding access and quality since its inception. Certain areas, however, are known for the high functioning of SUS with Florianópolis, SC, the main area for this research, being one of them. While some participants in this research had complaints about SUS, all acknowledged it functioned significantly better than other regions, and in some cases, felt its level of care surpassed private care. Florianópolis was also home to a strong counter culture movement, with many forms of integrative medicine available inside and outside of SUS as well. One of these modalities was Anthroposophic medicine (AM) – a form of medicine that is included by law into SUS, but has yet to be integrated throughout most of the country including Florianópolis. AM has carved out a space for itself in the region, however, attracting patients from a wide range of demographics and neighborhoods across the island.

Most healthcare choice models based around access, cost, perceived efficacy and others would lead us to assume that a relatively unknown form of medicine that was expensive and isolated would have a limited following in a medical landscape that offered free biomedical care at every neighborhood health post. Yet, AM has a dedicated following on the island, with highly satisfied patients who believe in the power of biomedicine yet find themselves choosing a form of medicine that can be financially burdensome, a distance to commute to and whose doctors never advertise their services. What, then draws individuals to AM in the wake of so many barriers and other attractive alternatives? What underpins these medical choices? This research illustrates the promises of citizenship under the 1988 constitution and how they became amalgamated with an ontology of personhood transmitted in the national healthcare system (SUS). This research argues that AM patients have reimagined these norms and ontology of personhood put forth by the 1988 Brazilian constitution to craft their own unconventional

citizenship and understanding of the self, and that this process has affected how patients make medical choices.

2.2 OUTLINE OF THE DISSERTATION

This dissertation consists of six chapters: Chapter One provides an overview of the bodies of theory that articulate to provide the theoretical basis for this research. The chapter begins with a review of the dominant literature in biopolitics exploring the role of biomedicine and national institutions' ability to promote national culture and manage citizens. This section also examines medicine's role in social norms, nationalism and the state**,** and the institutionalization of the protection of biovalue through health as a human right. The section on biopolitics concludes with an examination of membership, risk and medical participation through the lens of biocitizenship and biosocialities. Chapter One continues with a survey of the germane literature on health systems specifically exploring the globalization, transnational healthcare and the geopolitical forces shaping medical systems, as well as the hierarchizing of medical care through struggles of authenticity and legitimacy in pluralistic healthcare landscapes. Integrated with this section is an examination of medical pluralism addressing issues of medical integration and the negotiation of conflicting medical and cultural constructs. Chapter One concludes with a discussion of the interconnections between patient choice, biocitizenship and healthcare systems.

Chapter Two provides a description of the field site. A brief historical account of the evolution of Brazil's healthcare system is given. These descriptions include a concise history of the integration of AM within Brazil and the increased role that integrative healthcare practices

play in the medical landscape and specifically within SUS. Chapter Two concludes with a description of the methodologies used for site selection, data collection and analysis as well as the limitations of this research.

Chapter Three examines the construction of personhood through SUS beginning with the joining of democratic reform in the 1980s and the construction of health as a right of citizens and the role these historical events and narratives play in SUS physicians' view of the system and approach to patient care. This chapter explores the role of SUS and its healthcare agents within Brazilian society and the healthcare network as well as the impact these visions have on SUS physician's approaches to their patients. It also examines the current challenges to national healthcare network and a look at the predominate users of SUS in the region. Chapter Three also includes a consideration of SUS physicians' perceptive of *Practicas integrativas e complementares (*PICS), and Anthroposophic medicine. This chapter concludes with SUS physicians' perspectives on patient choice.

Chapter Four examines the construction of personhood in Anthroposophic Medicine beginning with an introduction to AM, its beginnings and various forms of treatment and specialties, as well as previous research on its uses, effectiveness, approach, and attractiveness to patients. This chapter also explores some of the barriers to implementing AM outside of central Europe, including its integration into medical practice in Brazil. Chapter Four continues with a survey of the approach to AM care through AM physician narratives as well as data from 70 hours of AM training in the field. Chapter Four concludes with a look into AM's non-conventional construction of personhood and how this is deployed in practice.

Chapter Five focuses on the perspective of SUS and AM patients and the intersection of the construction of personhood in medical care and citizenship. The chapter begins with a brief

introduction to patients view SUS and how these perceptions are tied to healthcare seeking strategies and treatment choices. This chapter continues by addressing the doctor-patient relationship and rights-based personhood, focusing on the perspectives of SUS and AM patients respectively on the rights and responsibilities of doctors. This examination of personhood from patients' perspectives also includes how SUS and AM patients view the responsibilities and rights of patients. The next section of this chapter focuses on the construction of non-conventional Brazilian biocitizens through AM care specifically addressing the AM patient's unique perspectives on health, disease, the life course and the medical gaze. Chapter Five concludes with a discussion on the intersection of personhood, biocitizenship and patient choice.

The final chapter is the conclusion for this research. Chapter Six addresses the need for a recapitulation of medical pluralism and patient choice through the lens of the ontology of personhood and the significance these ontologies have for biocitizenship. The chapter concludes with a brief discussion for the implications for the study of choice and personhood outside of medical care.

3.0 CHAPTER 1: THE THEORETICAL AND CONTEXTUAL BASIS

This research explores the production or rejection of state visions of the citizen through participation in both SUS and non-SUS healthcare systems showing how the ontologies of personhood produced in these systems influence biocitizenship. My theoretical framework draws on the literature on biopolitics, health systems and medical pluralism to re-conceptualize patient choice. Beginning with biopolitics, the chapter explores the role of medicine in social change, constructions of nationalism and the legitimazation of the state. The institutionalization of the protection of biovalue is directly connected to discourses on human rights and the benefits of citizenship. Healthcare has become a marker of citizenship in countries like Brazil that have universal healthcare programs. State-sponsored healthcare has a number of implications for the management of citizens and the creation/dissemination of rights and responsibilities of citizens. Membership, risk and medical participation have been shaped by the ideals and values embedded in biomedical care offered through state healthcare systems.

Medicine has been shown to be a means for the transformation and management of populations and infrastructures, participation and the responsibilities and rights underpinning new constructions of citizenship. Concepts of biology inherent in health systems have served as the foundation for new claims to membership, rights, and social mobilization. By introducing and shaping conceptions of personhood and the fundamental understandings of what it means to be human, (bio)medical care has the ability to shape perceptions of risk, responsibility and

entitlements. Biomedicine is only one of many forms of care operating in the health market, albeit one with considerable institutional support.

The role of healthcare in shaping ontologies of personhood is complicated by the introduction of other forms of care that compete, complement, and cooperate with mainstream health systems. With a rise in the demand for health care, countries such as Brazil are attempting to expand their services and are creating policies of inclusion of complementary and alternative health care systems to expand healthcare access. *The Política Nacional de Prácticas Integrativas e Complementares no Sistema da Sáude* (National Policy on Integrative and Complementary Health Practices in the Unified Health System) enacted in in Brazil in 2006, reflects this trend. In March 2018, SUS expanded the *Prácticas Integrativas e Complementares* (PICs) to include a total of 29 integrative and complementary practices within the system (Valadares 2018). Programs and projects like the PNPIC are also marketed as progressive democratic state projects. Healthcare is being increasingly viewed as a protection owed to citizens on the basis of their biovalue. Rights discourses, like those that underpin biovalue have augmented the demand for a greater variety and access to medical services. Governments like Brazil that offer universal care to meet this rising demand are also able to legitimize their governing structures and extend their influence to reinforce a relationship between citizens and the state. The services governments provide also enable the production and transmission of a certain view of the citizen. Patients interacting with the healthcare systems are not without agency to reject the conventional view of the citizen embedded in a state medical system, however, and are able to resist this view through their medical choices.

Brazil's unified healthcare system, SUS, operates in a pluralistic healthcare context, and with enactment of the PNPIC, has diversified the forms of medical care included in public services. The chapter includes an examination of health systems and medical pluralism since medical movements are utilized across national boundaries and competition between systems creates medical hierarchies that lead to struggles over legitimacy and integration. The rising tide of integration programs like PNPIC has implications for the integrity of integrative medical systems. Therefore, this chapter also addresses how the conflicting constructs between medical systems are managed and some of the social, political and economic considerations that contribute to these negotiations. Since patients are the sites of many of these struggles, I include a review of the literature on patient decision-making models as well.

3.1 BIOPOLITICS

Questions of political shifts and their intersections with citizenship, rights, and developments in science laid the ground for a variety of scholars attempting to untangle what it means to be a human being in these competing regimes of truth and value, creating the body of literature we know as biopolitics. Coined by Swedish political theorist Rudolph Kjellé in 1905, biopolitics was developed most prominently by scholars such as Agamben, Negri and Foucault in an attempt to define and delineate sovereign power and transitions in power formulations in a growing neoliberal and globalized age (Agamben 1996; Cooter and Stein 2010; Esposito 2008; Foucault 1963; Foucault 2010). The concept of *biopolitics* was formulated to capture how geopolitical interests (i.e. political and economic interests of nation states, and their management over all aspects of life) converged to create neoliberal movements to instill democratic

citizenship. The privileges of democratic citizenship are usually unevenly distributed, however (Arnold 1993). Biopolitics[1] involves the discourses about the vital character of living beings, the intervention placed on citizens in the name of the protection of life, and the means of subjectification through which modes of authority and their discourses are embodied (Foucault 1963; Rabinow and Rose 2006). Biopower, in this schema, is the rationalized attempts to intervene on the characteristics of human existence (Rabinow & Rose, 2006, p. 197). Crandon-Malamud (1991) captured this new biopolitics as a way to examine the complex and the evolving dynamic between the body (the citizen), their state and globalizing modernity. The body has become a foil to understand the transformation of social contexts and their articulation with larger structural contexts since the body can be a site for the construction of authority, legitimacy and control. Implicated in this process is the use of medical knowledge (Crandon-Malamud 1991). The body is an ideal site for regulatory and disciplinary techniques where on the one hand the body is "*individuated as an organism endowed with capacities*" while also being part and parcel of large population level management (Foucault 2003; Greenhalgh and Winckler 2005; McNay 2009).

Scholars like Agamben (1996) began with conceptions of biopower in the negative sense – the exercise of sovereignty derived from the ability to isolate and take (bare)life (Mbembé and Meintjes 2003). In this manner, sovereignty belongs to those who exercised authority over vital human existence, determining the value of life and retaining power over death. This power is perpetuated by producing and regulating the "biopolitical body" (Agamben 1996; Genel 2006). Agamben's approaches deviate slightly from Foucault's, borrowing greatly from Schmitt and

[1] Here Novas and Rabinow define biopolitics "*to embrace all the specific strategies and contestations over problematizations of collective human vitality, morbidity and mortality; over the forms of knowledge, regimes of authority and practices of intervention that are desirable, legitimate and efficacious*" (Rabinow and Rose, 2006).

focusing on violence (Genel 2006). Foucault abandoned discussing sovereign power and focused on the management and regulatory endeavors of inclusion and exclusion through institutions like state hospitals, prisons and asylums in his discussions of sovereignty specifically on "biopower." While biopower did not replace sovereign power in the nineteeth century, it did penetrate it (Foucault 2003; Genel 2006). Foucault attributed this shift in regimes of power to the fact that:

> Far too many things were escaping the old mechanism of the power of sovereignty, both at the top and at the bottom, both at the level of detail and at the mass level. A first adjustment was made to take care of the details. Discipline had meant adjusting power mechanisms to the individual body by using surveillance and training ... And then at the end of the eighteenth century, you have a second adjustment; the mechanisms are adjusted to phenomena of population, to the biological or biosociological processes characteristic of human masses. This adjustment was obviously much more difficult to make because it implied complex systems of coordination and centralization (Foucault 2003).

This new form of control was aimed at managing the population through technologies of power internalized by individuals and normalized by law but extending beyond state apparatuses and institutions (i.e. extended outside of the juridical order) (Foucault 1990; Genel 2006). Aretxaga explored similar shifts in policy showing how territorial sovereignty and homogenous definitions of the (Weberian) nation-state[2] were being challenged by diasporic forms of identity (refugees) and private companies and institutions (including NGOs, aid organizations etc.) usurping the functions of the state (Aretxaga 2003; Castañeda 2007). She also showed that globalization fueled the desire for statehood, and governments have responded by actively promoting national cultures and narratives though many of the institutions Foucault implicated in

[2] The "State" has ambiguous definitions and positions. Acknowledging its short comings Aretxaga has pointed out: "In writing on political institutions there is a good deal of discussion about the nature and origin of the State, which is usually represented as being an entity over and above the human individuals that make up a society, having as one of its attributes something called "sovereignty," and sometimes spoken of as having a will (law being often defined as the will of the State) or as issuing commands. The State in this sense does not exist in the phenomenal world; it is a fiction of the philosophers" … "the difficulty in studying the state resides in the fact that the state -- as a unified political subject or structure – does not exist; it is a collective illusion, the reification of an idea that makes real power relations under the guise of public interest" (Aretxaga 2003).

"governmentality[3]" and "biopower." This has created complications with many actors competing for the functions of the state and citizens struggling for full citizenship attached to national discourses of the state (Aretxaga 2003).

Foucault's project was in part a historical conceptualizing of world health as biopolitical. Health and hygiene were intrinsic elements of global biopolitics and modern regimes of power (Bashford 2006). Governance of world space through the standardization and cooperation of international epidemiological intelligence networks broadened Foucault's "quarantine logic" and "governmentality" outside of sovereign borders to "national biopolitical states and their colonial extensions" (Bashford 2006). This was also an important development in "the administration of life" and spread of biomedicine and its accompanying values, methods and standards since global networks require standardization of knowledge and regulation to be functional (Bashford 2006).

Rose and Rabinow adapted Foucault concepts to create a nuanced framework that acknowledged (like Foucault) how forms of power shifted over the eighteenth and nineteenth centuries. Toward the end of this trajectory, technologies of biopower lent themselves to a new style of management through governmentalized states and their health, welfare and security programs as well as by philanthropic organizations (Rabinow & Rose, 2007, p. 204). New regimes of truth around individualization, autonomy, rights and value embedded in vital terms or biological truth extended the reach of these technologies of biopower. They introduced a *conduct of conduct* through the logic of "responsible self-management" and a political economy based on vitality, scientific knowledge, and biological material (McNay 2009; Rabinow and Rose 2006;

[3] Governmentality denotes "*a modern form of political rule, the legitimacy of which is derived not from the wisdom, might or religious sanction of the sovereign but from the 'rational' ordering of men and social affairs*" (McNay, 2009: 55-77).

Shaw 2012). Autonomy was at the heart of neoliberal governance and transformed conceptions of responsibility and risk by pairing discourses of individual freedom and modernity with science and regulation of social practices (Greenhalgh and Winckler 2005; McNay 2009).

Biopolitics is also involved in the relationship between "modernizing" projects, science and the state. Universal health care narratives often emphasize individual responsibility where both public (public health and federal) and private (pharmaceutical companies, private health and insurance organizations) interests are internalized (Tamar 2014). Medical science is directly implicated in this shift in responsibility since, as Bruno Latour shows, specific technologies encourage certain types of behavior such as the active participation within medical knowledge and adoption of medical advice (Tamar 2014). As Clark et. al. has shown, biomedicalization of life has expanded medicine's reach into new areas such as law and morality, allowing for the shaping of cultural norms, notions of identity, entitlements and responsibility. Contemporary medicine has contributed to a recasting of risk and individual and collective identities acting as a cultural force through the various ways in which power is built into the clinical gaze and embodied in social practice and norms (Clarke, et al. 2010; Foucault 1963). Modern science projects and nation-states coproduce "modern societies" or members of a "modern polity" through the distribution of a certain kind of knowledge (Fan 2012). Inclusion within the system made individuals subject to this medical gaze and the value assigned to them through this ideological system (Grewal 2005). The following sections will address the themes of social change, nationalism, health rights and biocitizenship in greater detail below.

3.1.1 Medicine's role in social change, nationalism and the legitimation of the nation state

Virchow once argued that politics is nothing but medicine on a grand scale. Virchow recognized that medicine and its practitioners were often politicized and that medicine and medical research were not only influences in themselves but products of social relations (Adams 1998). Many anthropologists have investigated how cultural change and medicine and politics intersect. Vincanne Adams' work is a classic example of how medical transitions and discourse become implicated political struggles in multiple ways. In Tibet, the influx of biomedicine was associated with a "modernizing" Chinese development project (Adams 2001; Adams 2002a; Adams 2002b). In Nepal, medical professionals became politicized in the struggle against the monarchy by disseminating "subversive" information, participating in strikes, sheltering opposition leaders in health facilities, giving civilians (rather than soldiers and police) priority treatment and advocating for universal human rights under the langue of "democracy for health." The politicization of scientific activity was so extensive that after the revolution, many patients assumed that most (if not all) health programs were in fact political campaigns to garner favor and votes. Separating party politics from health in the public imagination became difficult, if not impossible (Adams 1998).

The importance of medical care to politics can be seen in a variety of contexts especially during national administration shifts. Medicine is a means to shape and disseminate new cultural ideology (Smith-Nononi 2010). Brotherton and Andaya have both showed how healthcare workers form "moral collectives" embodying the essence of revolutionary principles. Both use Cuba as an example to show how "*universal public health care has been central to the socialist vision of an egalitarian society and to official narratives extolling the victory of moral and social justice over capitalism's materialism, utilitarianism, and inequality*"(Andaya 2009; Brotherton

2012). The provision of healthcare as a right of all Cuban citizens was (and is) used to support claims that the "new" administration was both modern and morally superior for audiences at home and abroad. Doctors embody the principles of "the new man" that included ideals of self-sacrifice and collectivism. Doctors were not only exemplars of the new citizenship ideology, they were also the means for sustaining an ongoing reciprocity and solidarity between citizens, practitioners and the state (Andaya 2009; Brotherton 2012). Physicians have also been ambassadors for socialism and by serving overseas they engage in "medical diplomacy" and help secure international good will, alliances and material benefits (Andaya 2009). Here one can see how medicine is used as a symbolic device to create a certain imagination of the state.

> States are not simply functional bureaucratic apparatuses, but powerful sites of symbolic and cultural production that are themselves always culturally represented and understood in particular ways. It is here that it becomes possible to speak of states, and not only nations, as "imagined" – that is, as constructed entities that are conceptualized and made socially effective through particular imaginative and symbolic devices that require study (Ferguson and Gupta 2002).

There are numerous examples of how biological principles (within or outside of medicine) can be used to organize politics and national identity in dynamic ways and how nationalism and capitalism are intertwined with biological discourses (Collier and Ong 2005; Farquhar 1994; Gupta 1992). Bucur's work on how social reform and biological determinism led to the Romanian "brand" of eugenics to create optimal and "authentic Romanian" citizens (Bucur 2002), Ong's exploration of competing and flexible identities forged through participation in international markets and "capitalists zones" (or zones of exception) (Ong 1999, 2006), or Kanaaneh's ethnography on how the contested nature of "true" nationalism is embodied in fertility choices, family size and desires to be both traditional and modern, are all cases in which one can see the range of biopolitics, nationalism and social mobilization (Kanaaneh 2002).

3.1.2 The institutionalization of the protection of biovalue through health as a human right

Healthcare is implicated in a number of public and private interest projects. The entanglement of private and public interests in healthcare can assist in introducing and institutionalizing specific values and practices, which bleed into a variety of other arenas. As Janes showed in his work on medical pluralism, colonial public healthcare programs in India were originally enacted to protect British soldiers and residents abroad from disease and to ensure that sickness was not imported back to residents in England. The British public health system was concerned with the identification and protection of *specific* subjects deemed valuable. Public health care practice was later expanded as a modernizing and civilizing project for the social transformation of the "others." It also became a ground for contesting British benevolence when their "colonial subjects" were underserved by these services (Janes 1995). Thus healthcare both reflects and creates systems of value as well as state ideology and practice. This is not unlike Brazil, where the provision of healthcare for all was seen as a "civilizing" principle and a marker of social progress.

The increasingly transnational nature of political economy has not only made health systems more dynamic, it has created new challenges to "traditional" forms of state spatialization and management (Ferguson & Gupta, 2002). States must retain their verticality with "top-down" management or maintaining its higher functions, and encompassment. The metaphors through which states are imagined are directly linked to social practices like the provision of universal healthcare to join top-down processes with encompassing the "bottom" or the local. These metaphors are not only important for maintaining "the mandate of the people" they are also important in creating a national imagination of the citizen (Ferguson and Gupta 2002).

Foucault provided the first step – the realization that populations are governed by institutions, agencies (both state and private), and the norms and identities that these entities construct (Foucault, 1990). These institutions or agencies can be both subversive to state projects but can also enable wider appeal of the government among international and resident actors (Fassin, 2007; Ferguson & Gupta, 2002, p. 98). Neoliberalism involves a decentralization of state functions in favor of transferring operations of government to private entities, creating new strategies of discipline and regulation that are nevertheless associated with the state (both foreign and domestic). These institutions gain legitimacy through "democratization" becoming key players in a system of transnational governmentality able to enact policies that are in fact undemocratic (Ferguson & Gupta, 2002, pp. 990, 993) This means healthcare systems are not only competing with one another, they can be attached to struggles over sovereignty, "development" and their particular ideologies that are potentially in opposition. Healthcare is implicated in systems of global "good" governance. Rationality is not only a dominant Western value; it is where values are hidden (Gordon, 1998, p. 39). Gordon points out how biomedical practice is connected to notions of individualism and Western ideals of freedom and autonomy (Gordon, 1998, p. 33). This makes healthcare an important site for the enforcement of self-regulation and techniques for discipline and care of the self (Foucault, 1991; Gordon, 1998). It also makes healthcare a stage for claiming rights (Gordon 1998).

While some of the behaviors and policies associated with "good health and good citizenship" are packaged as concrete, the meaning of health is indeterminate,[4] especially when it is in service of politics (Baer, et al. 2012; Greco 2004). Health has been moralized, acting both as a (moral) good and as a means of designating certain behaviors (associated with health) as

[4] Greco defines indeterminacy in this case as having "*no organic norms of health but only socially and morally contestable ones.*" ibid.

morally good (Metzl and Kirkland 2010). Human rights and their connection to discourses on biovalue have combined the idea that health is a good and a function of individual responsibility, with the idea that health (care)[5] is a right - an entitlement owed to humanity based on their *barelife*. Physicians, patients and governments are all involved in creating and maintaining assumptions and assertions about rights, responsibilities and morality packaged in the ideologies of healthcare and objective science. The right to health is itself a "biopolitical form of (medical) rationality" (Greco 2004; Petryna 2004b).

Rationality and "good practices" of health become intertwined (Bashford 2006; Morgan and Roberts 2012). "*Rational citizens are defined as those that embody and reproduce state-supported priorities in their values, conduct, and comportment*" allowing for "*the consideration of the links between embodied and biological moral regimes, national political strategies, and global economic logics, therefore linking 'intimate governance to world governance*"(Morgan and Roberts 2012:244). Human right introduces moral regimes[6] and discourses on how rights should be claimed. The extension of human rights into the domain of health creates competing frameworks of value and political and social hierarchies often embedded in alternative agendas (Fassin, 2007). "*Across this terrain, NGO's and the transnational advocacy networks play a prominent role as both agents of intervention and collective authors, gathering and disseminating authentic voices and specific facts in the name of values"* (Redfield 2006:18).

Numerous scholars have showed that humanitarianism creates a politics of life that has very real and potentially problematic outcomes (Fassin 2007; Redfield 2005; Redfield 2006;

[5] The right to health suggests a right to health care rather than health status since the parameters of health are variable or indeterminate despite the fact that it is usually posited as a static, given, or "normal" state of being. Definitions of health are also tied to specific forms of knowledge ibid.

[6] Here I use Morgan and Roberts' definition of moral regimes based on Foucault's regimes of truth i.e. "*the privileged standards of morality that are used to govern intimate behaviors, ethical judgments, and their public manifestations*" (Foucault, 1990).

Ticktin 2006). Fassin's "politics of life" references these effects ranging from how rights are defined to who is deemed deserving and how humanitarianism, legitimacy and social capital are interrelated. Rights claims and accompanying social action are far from homogenous. The right to life for unborn children, for example, may stand in direct opposition to the expansion or protection of reproductive and sexual rights (Morgan and Roberts 2012). Who is deemed deserving and who is included in competing notions of "natural" human rights open the field to new actors, means of claiming rights and contestations of identity.

3.1.3 Membership, risk and medical participation: biocitizenship and biosocialities

The biotechnical age of healthcare has created new conceptions of what it means to be human and the responsibilities and rights owed on the basis of these definitions. Neoliberal governments have shifted responsibility further towards the individual re-conceptualizing risk (Halse 2008; Harwood 2008). As Rabinow noted, we are "*moving away from face to face surveillance to projecting risk factors that deconstruct and reconstruct the individual or group subject"* (Rabinow 1996:100-101). The re-territorialization of human nature or the molecularization of life has not only created a new conception of what it means to be human, it also opens patients up to the political economy of hope and risk management. Genetic responsibility is an additional level of the individualization of health and self-care as part of the global discourse of responsibility in "Western" societies that has shifted traditional public concerns to the private sector (Braun 2007; Harwood 2008; Tamar 2014).

> Responsibility for securing health for oneself and for those to whom one owes allegiance is now based on the individual actor, who is required to exercise prudence in the light of expert assessments of risk … risk is argued to be a central organizing principle of post-industrial societies, linked to not only the management of late modern identities but also involved in the governance of individuals and population (Possmai-Inesedy and Cochraine 2013:68).

Nyberg showed this in his work on how national sick day policies in Sweden further organizational control and influence the local process of sickness and absences from work. These policies shifted responsibility to citizens to avoid and manage illness and maximize efficiency and workability (Nyberg 2012).

Responsibility and the understanding individuals have of themselves as human beings and as accountable citizens has been greatly influenced by biomedicine, biotechnology and especially by genetics. Genetics has shifted the onus of good health onto individuals, and has opened them up to new forms of medical surveillance. It has also linked individuals to entitlements. Genetic risk, has created a mutation in personhood or what Novas and Rose called "somatic individuality" (Novas and Nikolas Rose 2000). Somatic individuality is intertwined with ideas of genetic risk, responsible personhood, and social ties (family and community) that are involved in passing on genetic inheritance (Novas and Nikolas Rose 2000). An example of somatic individuality can be seen in Rapp's work on amniocentesis and how changing perceptions of risk with the medicalization of pregnancy created ambiguous determinations of value and responsibility. It changed the conceptions of responsible birth practices in light of genetics. Responsibility to partake in the test as an "older" expecting mother was associated with being a good patient. Competing notions of value and responsibility were also involved in choosing to continue or terminate pregnancies when the fetus tested positive for genetic abnormalities, and practices of genetic counseling (Rapp 1999). These positions were highly variable and open to interpretation.

While genetic risk is individualizing, risk as it pertains to biosecurity is collectivizing. Individuals can be vehicles for dangerous pathogens, and therefore, a threat to other people. This

collectivizes risk and makes the body a site of state determination and control for the protection of "biovalue[7]" i.e. "biosecurity[8]"(Barker 2010; Braun 2007). A contractual relationship with the state where predetermined citizen virtues and their accompanying duties, rights and expectations are solidified in legislation to form "biosecure citizenship" and an extension of traditional boundaries of the state become justified through a "biosecurity regime" (Barker 2010; Marshall 1950).

> The extension of citizen obligations to the private sphere is reliant on the willingness of the public to participate. Biosecurity and the accompanying stringent legislation do not operate in an ideal scenario of public compliance, however, and generating public concern is not easy. It is in this concept that non-contractual citizenship obligations and the utility of the citizenship discourse in the attempted normalization of pro-biosecurity behavior are significant (Barker, 2010, p.359).

Risk and citizenship ideology are integral to obtaining public participation in "positive biosecure behavior" while avoiding being cast as an over-extension of sovereign power (Barker, 2010). An integral part of this normalization process is the somatic individualism and normalization of functional and dysfunctional categories (Katz and Marshall 2004). The medicalization of the social sphere has expanded ideas about the functional/dysfunctional categories that enable the powers of expertise and the governance of everyday life across a broader horizon of human problems (Katz and Marshall 2004). Biotechnology introduced more refined ways of measuring functionality of living beings on a biological level standardizing or creating ideal states to define "normal" vs. unnatural, functional vs. dysfunctional. This could be

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[7] As Birch and Tyfield point out, "biovalue" has been used ambiguously to refer to market practices or in terms of ethics and meanings. For the purpose of this research, I will use this term as it relates to linking "vitality and value" but will not attempt to tease out the nuances between surplus value, moral value, capacity and capital that Rose, Lock, Franklin and Walby have used with this term (Birch, Kean, and Tyfield 2013: 299).

[8] Biosecurity was defined by the Biosecurity Council in 2003 as "*the exclusion, eradication or effective management of risks posed by pests and disease to the economy, environment and human health*" (Barker, 2010: 351).

called “posthuman informatics,” an attempt to create a biological microscopic universalism that was measurable, standardized and available to intervention shaped by cultural flows, information technologies, experts and citizens (Katz & Marshall 2004; Halse 2008; Harwood 2008). As Novas and Rose point out in their work on Bio-identities:

> The vital politics surrounding functional/dysfunctional states and post- human bodies produces new personal realms of identity-formation tied to ethical and reflexive practices. Specifically, as we come to understand ourselves in terms of the life-strategies, risk-managing skills and universal rights associated with ‘biological ethics’(Katz and Marshall 2004; 60).

Personhood derived out of biomedical technologies and life sciences is not limited to genetics. Biomedical intervention has created new terms of kinships (birth mother, egg donor, biological mother) and modes of self-identification and conception. While functionality is linked to individual responsibility to be a member of a functional population (a productive citizen) it is also directly entrenched in contemporary norms that stress choice, responsibility, individuality, self-actualization and the behaviors associated with these categories. Genetics opened the space between the body and the person and now individuals are positioning themselves in relation to one another and to the state biocitizenship, where biology is utilized by multiple actors to govern as well as claim entitlements, i.e. “biocitizenshp.” The corporeal body has become a site where politics, issues of membership, rights and obligations are formed and contested (Rose 2001a).

> Biological citizenship emphasizes the way we are increasingly coming to relate to ourselves as ‘‘somatic’’ individuals . . . as beings whose individuality is, in part at least, grounded within our fleshy, corporeal existence. … In this formation, citizenship is refracted through our intimate corporeal associations with our own fleshy human body, and increasingly, our molecular individuality made known to us by biomedical science (Barker, 2010, pp. 352-353).

Nationality has often been understood in (partially) biological terms. Routine practices of medical care and biological education are both a national priority and a means through which

citizens view themselves (in part) as a biological entity. It is in biological citizenship[9] that risk, rights, and membership coalesce. Biocitizenship operates within the political economy of hope, where responsibility to pursue "health" and the power of biomedical intervention meet the right to healthcare (Rose and Novas 2005). It is also where conceptions of shared identity[10] based on biology engender a space for biosocial groupings – "biosocialties." Biosocialities are a way for individuals to gather around a condition and expand access to resources and knowledge (Rabinow 1996). As such, biosocialities are often associated with forms of medical activism and advocacy. The deaf community is an example of how biopower is not simply the colonization of life and the body or an imperialist tool in the making of state power. Biopower can also be productive in creating community and in resistance to other forms of power and boundary work. In other words, subject making is not only a top-down process since resistance is not the opposite of power but a form of developing alternative relationships with themselves, the state and society. Power initially predicated upon the medicalization of life and ensuring regulation can also be the site where new forms of community, identity and rights can be formed (Friedner 2010; Petryna 2004b; Rabinow 1996; Shaw 2012).

[9] By making up citizens Rose and Novas are referring to how biomedical languages and concepts, health education, medical advice, media and the linking of support groups get used to "*create persons with a certain kind of relations to themselves.*" (Novas & Rose, 2005, p. 12)

[10] Taussig (2009) has also noted that shared acceptance of scientific principles is a means of marking oneself as common with shared "Enlightenment heritage."

3.2 HEALTH SYSTEMS: GLOBALIZATION, TRANSNATIONAL HEALTHCARE AND THE GEOPOLITICAL FORCES SHAPING MEDICAL SYSTEMS

Tracing the effects of biopower and the construction of citizenship through medical systems requires an examination of the nature of health systems themselves and their relationship with wider contexts like biopolitics, medical pluralism and the State. Anthropologists have long explored the multiplicity of health systems with an emphasis that has shifted from studying local healing practices in one community to the ways in which these practices form health networks that grow, cross borders, and interact with different traditions and ideologies[11]. This has given rise to a history of contested conceptions of (and approaches to) medical pluralism and health systems. Medical pluralism began its wider popularity in 1960s and has evolved from to documenting the medical aspects of specific cultures incorporated in ritual and magic to examining the co-existence of medical practices while also acknowledging issues of power within the larger historical, social and political contexts of these areas (Ernst 2002; Lock and Nichter 2002). Later evolutions of the study of medical systems, inspired by Charles Leslie, encouraged scholars to conceptualize alternative systems as coherent traditions and part of pluralistic structures where practitioners of different traditions took on multiple roles. Charles Leslie's work illuminated the fact that medical systems were often given different statuses reflected in terminology that deemed some systems as "alternative" and others as "mainstream."

While Charles Leslie did not explicitly address larger questions of domination and globalization (Khan 2006), he captured several important factors relevant to the medical

[11]Here I use Kleinman's definition of health systems as a cultural system - a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions' (Kleinman, Arthur 1980b).

landscape in Brazil and the ways in which integrative healthcare practices are positioned as complementary or "alternative" despite being given entre in the nationalized public healthcare system (SUS).[12] Leslie asserted that being given an alternative status made these systems vulnerable to "improvement" and "standardization" strategies aimed at removing "irregular practices" to make local medical systems extensions of a national and international standardized medical system. The standardization process has effected what medical modalities were deemed appropriate to include in SUS regardless of whether these modalities were endemic to Brazil or were introduced through colonialism, immigration and globalization. It also meant many of these modalities are operationalized with a biomedical ontology of personhood rather than their "traditional" ontologies.

In analyzing how health systems were transported and interacted with other systems, colonialism provided a valuable platform to examine the circulation of medical systems and the syncretism, and annexation that followed (Unschuld 1975). A prime example of this scholarship is the that are endemic to Brazil or were introduced through colonialism, immigration and globalization study of humoral medicine, which diffused throughout the Old World (Greece, Rome and Moors) and was transported to the New World. Humoral medicine provided evidence for syncretism in the striking similarities that scholars "discovered" between Chinese, Indian and Greco-Roman systems (Foster 1994; Logan 1973). Humoral forms were transported to the New World and continued to take on new forms. Logan showed how certain elements of the Hippocratic theory were introduced into Latin America by colonial forces and were altered by local powers and actors to integrate with existing concepts. This is reflected in New World variations that deemphasize moisture in favor of temperature (Logan 1973). Foster showed

[12] Throughout this research I will refer to non-biomedical medicine integrative medicine since the term *integrative medicine* avoids the loaded dichotomization of "alternative" vs. mainstream." Cant and Sharma 1999).

similar patterns of migration and evidence for Old World influence and introduction of new ideas about illness, classifications and practices that could have syncretized with local traditions since there were local variants that are absent form the Spanish "Old World" practices (Foster 1994). These "Old World" practices are still present in Florianópolis, preserved in home remedies, tea shops, everyday social norms about health and now in the medicinal gardens of SUS health posts. While these practices have been in some ways recast in their new role within public healthcare, they are nevertheless important to making national healthcare in Brazil "Brazilian."

Colonialism was an optimal lens to see how medical systems, especially biomedicine, spread and evolved in new contexts and were inevitably tied up with political agendas and projects. Janzen addressed this power dynamic in his work on West African therapies and local traditions, which were regulated or all out rejected and transplanted by Western medical institutions and colonial forces in an effort to modernize Kongo (Janzen 1978). Prophet seers and magic healing were considered a potential source for conflict and politicization. Belgian colonial forces made alternative forms illegal and injected Western medical institutions and laws, permits to practice etc. for the treatment of disease. Other studies of colonial intervention highlight healing as a symbol of authority wielded by a variety of public figures in the name of "public restoration." Biomedicine was deployed and extended through health and sanitation concerns as a modernizing project and as a means to protect "white health" in many colonial contexts. The widening of the medical gaze exposed far-reaching sections of society that had varied responses ranging from acceptance to rejection. Dissent often stemmed from critiques that public health systems were underserving or undermining local society. As such it ran the risk of being associated with coercive and foreign empire (Janzen 1978).

Initial accounts looked at medical pluralism and the spread of medical traditions in the context of colonialism but later examinations of these medical traditions suggested the more mixing of local community, clinical practice and wider exogenous political forces exerting influence over the medical landscape. Arnold explored some of these power dynamics by examining the development of a Western medical paradigm adapted in India i.e. a form of colonial medicine that was different than the motherland marked by the appropriation and/or subordination of other local traditions. Wujastyk and Smith showed how "new age Ayurveda" was circulated and fueled by market demand often creating a reinvented "traditional" form (Wujastyk and Smith 2008). Janzen focused on how forms attempted to demarcate themselves from other systems in Colonial contexts. His approach complemented Kleinman's definition of health systems, by examining them as corporate groups. With the growing incorporation into the pluralistic medical system, maintaining "authenticity" required the medical systems to sustain a coherent body of beliefs and preserve this standard through professionalization. Legal codes and experts emerge, protecting this training and maintaining its integrity once this process has begun (Janzen 1978).

Colonialism has remained part of the discussion on the interaction of medical systems with the introduction of human rights rhetoric. Contemporary anthropologists addressed how human rights discourses and health intervention can be neocolonial and introduce (problematic) hierarchies of value (Epstein 1996; Fassin 2007; Ticktin 2006). Human rights discourse blends geopolitical and biopolitical forces together to create transitional connections that dictate new norms around modernity. Cosmopolitanism, for example, is not just a function of globalization but also of government policies reflected in health policies (Castañeda 2007; Wolff 2012). Briggs' work on the sexual and reproductive lives of Puerto Rican women is prime example of

the ways in which anthropologists discuss the debates and influences of imperialism and the role of science, medicine, and technology in this relationship. Biomedical intervention and redefinition of identity is a way to rationalize "othering." The focus on "tropical diseases" (venereal diseases) by U.S. officials in Puerto Rico, for example, marginalized and limited Puerto Rican citizenship. Puerto Ricans were cast as different and belonging to a culture of poverty whose problems stemmed from a lack of constraint over reproduction (Briggs 2002).

Briggs's work exposes the potential of neocolonial science to shape power relations and discourses on value and identity. Her works also showed how these discourses were appropriated by Puerto Rican health professionals and politicians for their own power, authority and legitimacy using women's bodies as political tools (Briggs 2002). Power dynamics born out of (and reflected in) health policies extended U.S. legitimacy for intervention on the international stage achieved through constructing modern progressive subjectivities on the mainland and stigmatizing Puerto Ricans. Science as ideology was proof of U.S. benevolence. The rhetoric of control of diseases associated with people of "low morals" and the association of tropical and venereal diseases with people at the metropoles and minorities, disguised power relations, economic exploitation, and unfair terms of trade. Women were reproducers of third world threats, turning family planning into the linchpin of "democratic capitalism" producing Puerto Rican difference and denial of U.S. influence (Briggs 2002). The booming increase of Zika in the global south, is recasting this narrative in which women face criticism over not preventing or delaying pregnancy and burdening the system with children with microcephaly.

Changes in financial and health constraints have opened up the healthcare market and allowed for greater incorporation of integrative medicine. Part of incorporation has to do with the fact that traditional medicine may be in higher demand with the rise of chronic diseases. The

health transition creates higher demands for alternatives (especially if they are cheaper) while at the same time government policies are often limiting or sanctioning these systems. The World Bank (1993) recognized the increasing demands that health systems would face with the double burden of disease and suggested including local health services if they were worthy of public investment as cheaper alternatives to rising health needs and costs. Incorporating multiple health systems does not lead to a neat folding over of one system within another, however.

Mixture of health systems is largely taking the form of syncretism or the incorporation of one system with another. This often means that standards of quality, safety and proof from one system become grafted onto the incorporated system. Domination is one element of the larger process of globalization and many indigenous institutions find themselves choosing exclusion or submission to Western scientific epistemology. Legitimation, professionalization and market competition lead to local variants of transplanted health systems that have adapted / absorbed into biomedicine (Janes 1995; Janes 1999; Janzen 1978; Lock and Nichter 2002). I will explore these power negotiations between biomedicine and incorporated health traditions, as well as excluded ones particularly in the wake of the PNPIC in chapter 3.

The crisis of non-dominant medical systems is to navigate absorption or inclusion while maintaining their core values and approaches. Many systems are "playing ball" in order to continue to compete in the health market. Janes gives an example of this with Tibetan medicine, which was included as a form within the Chinese medicine "family." While it has largely maintained its integrity as a form, Tibetan medicine has been transformed through training that emphasizes materialist conceptions of the body, and the inclusion of medical training into the government health bureaucracy making it part of a complex bureaucratic institution with new social relations and benefits of "Chinese citizenship." Recasting traditional practices and beliefs

within the dominant biomedical model has allowed traditional practitioners to continue to operate in a secular society, however (Adams 2001; Janes 1995). Brazil boasts the first residency program in Acupuncture outside of Asia. Yet, the way acupuncture is often taught and applied is heavily colored by Brazilian biomedical ideology now that it is part of SUS and state medicine.

Health systems often rely on the support of the government to operate. Lock's work in Japan (1990) highlighted this issue, by examining the selective legitimization of Ranpo in the 1860s in Japan during the Meiji restoration by power structures, such as the Dutch licenses. Ranpo was legitimated by governmental licensing practices, thus, de-legitimating Chinese Kanpo in the area, which was not made illegal but dwindled when Ranpo training was required before practicing Kanpo. With the rise of Asian nationalism in later eras, Kanpo was given credible status through political and governmental support. This harkens back to Janzen's examinations of corporate groups and how medical systems flourish if they are able to form and maintain clear boundaries as a distinct social entity with credibility and legitimacy (Janzen 1978). Myntti captures this same complex dynamic between competing regional and international ideologies, and the relationships between health systems arguing that education, economic differentiation, religion, and historical tensions between systems and hthe availability of remedies shape acceptability and notions of good care as well as the acceptability of biomedical *versus* traditional forms (Myntti 1988).

The mixture of medical systems is complicated but the fact that many patients use systems concurrently. Concurrent use is made possible by healers that serve other roles in local communities such as midwives acting as a support for mothers, taking care of the dead and conducting transitional rites. Medical systems are social systems that give meaning and form to illness experience (Leslie 1980; Parsons 1985). Health systems are an entry point for examining

the social processes and relations and can both represent and bridge conflicting entities outside of medical territories. Scholarship on health systems has included how the integration of medical systems can be a form of boundary crossing,[13] reconciling social, ethnic and political rifts. Medicine can be used as a boundary object to bridge political, ethnic, religious and professional borders, and as a site for collaboration and reciprocal learning and to translate/mediate diverse identities.

Health systems are ideal boundary objects because they are "*both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites"* (Keshet & Popper-Giveon, 2013, pp. 376-377). The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds (Keshet & Popper-Giveon, 2013). Anthroposophic medicine maintains a unique position in the healthcare landscape since all physicians are certified biomedical physicians with additional training. AM doctors do not see themselves as "alternatives" but as practitioners who expand the biomedical schema. This also makes them well-positioned boundary crossers and bridges between biomedicine and integrative health practices.

Belief in one form of medicine influences participation and relationships with other forms of medicine, assessment of illness and choice of treatment (Logan 1973). Examples of this can be seen in how "modern" medicine like Aspirin, penicillin and Alka-Seltzer are ascribed characteristics within the humoral system depending on the temperature and quality of the illness they are designed to treat (Logan 1973). The scholarships examining the interrelationships of

[13] "The term *boundary crossing* was introduced to denote how professionals at work may need to move and interact across different sites. Under the influences of postmodernism, poststructuralism, postcolonialism, and feminism, the concept of boundary crossing is likewise used to focus on the marginal and the de-centered as alternatives to discourses of the power of the center (Keshet and Popper-Giveon 2013).

health systems shows that modern medicine has historically extended its reach and been incorporated in unique ways. It does not necessarily replace these systems altogether but serves as an additional concurrent system as the case with humoral systems in Latin America or the expansion of the medical approach in the case of AM. Biomedicine becomes structurally and culturally dominant but does not entirely displace non-biomedical alternatives (Janes 1999). Health systems overlap and have contradictions or discrepancies that lead to the privileging of one system over another. This does not exclude the potential for productive boundary crossing, however, and has implications for examining cultural relations since health practices can show changes (or lack thereof) in social practices and culture (Logan 1973).

Leslie and many of his successors saw medicine's potential as a powerful force in modern history. Western medical projects were associated with the virtuous (and unquestioned) ends of saving lives and minimizing suffering. These projects often came with the explicit or implicit goal of assimilation to a transcultural medical science (Leslie 1980). Physicians were able to inject modern ideas through therapy, as well as the moral and social aspects of health and disease into local systems of medicine and knowledge production of healing (Leslie 1980). Leslie set scholars down the path to recognizing modern medicine on the same level as "irregular practices." He pointed out that biomedicine itself was pluralistic and that it should be considered a competitive or complementary component to alternative therapies when examined in a pluralistic medical setting (Leslie 1980).

Pluralistic settings can show trends in social, economic and political factors that affect choice and how illness acts as metaphors for social ills and treatment for these ills. "*The hegemony of one medical system over the others reflects the distribution of power in society*" (Myntti 1988:520). Indigenous systems are valuable in that they link suffering to wider social

and cultural phenomena. Yet, many integrate to survive becoming rationalized or sanitized to be scientifically justified (Janes 1999). Among the negotiation of inclusion and recognition is the fight for legitimacy and the chaos of navigating "democratized science." Epidemiologic transitions stirs up new struggles and questions of legitimate practice. The rise of new conditions or diseases such as HIV influences ideals of good practices as evidenced by how the variety of players, scientists, doctors, victims, government agencies, pharmaceuticals and even neighborhood communities became involved in HIV research. Credibility struggles over whose claims can and should be trusted entered official discourses on policy or procedure. Activists fought for credibility and legitimacy by becoming lay experts in biomedical research through their own "claims making" that led to community organization and altered forms of truth making about HIV (Epstein 1996). These epidemiologic shifts call into question larger questions of truth, authenticity and legitimacy. Patients and providers become key players in this negotiation of truth and authenticity. Medical choice can provide a window into how patients view and accept or reject these claims.

3.2.1 Medical hierarchies and the quest for authenticity and legitimacy

Hierarchies have formed both within medical systems and between respective systems fueled by market competition and the move to be recognized as both traditionally authentic and legitimate in the modern health market. Anthropologists have explored this tension between legitimacy and authenticity and the constraints of becoming acceptable and competitive as traditional forms. Many medical systems adapt to international markets trying to maintain authenticity as a "national form," and marketability and appeal as a transnational form. This is additionally complicated by the influence of medicine's role in the construction of nationalisms and cultural

boundaries (Alter 2005). The evolution of marginalizing integrative healthcare practices to selectively including it through a carefully monitored medical pluralism has been an uneasy transition largely pushed by governments trying to increase access and ease political struggle (Adams 2001; Cant and Sharma 1999; Janes 1995; Janes 1999; Wahlberg 2007). Such has been the case in Brazil with certain forms of integrative care gaining entry into SUS albeit under the administration of SUS and according to SUS principles of care and professionalization.

Professionalization often grafts traditional institutions onto biomedical models of specializations, training, epistemology and legitimacy under the rhetoric of public safety and efficacy (Adams 2001; Adams and Li 2008; Craig 2011; Fan and Holliday 2007; Janes 1995; Janes 1999; Wahlberg 2007). Some integrative forms are more readily incorporated into biomedical paradigms than others by forming their own professionalizing training and institutions. Hierarchies between these "alternative" systems highlight issues of legitimacy and authentic expertise. Recognized groups are state defined and selectively legitimated over time as certain traditions are reformulated and compartmentalized into systems of accredited knowledge (Lambert 2012). This poses significant barriers to legitimacy for the un-credentialed whose lack of accredited degree programs and reliance on experiential expertise disqualifies them as authentic and legitimate in the eyes of both biomedical and accredited medial forms/institutions (Lambert 2012). While these practitioners have expertise, they are not authorized to practice since legislation has rendered them marginal and lacking legitimate medical expertise (Adams 2001; Lambert 2012). AM has encountered several of these issues since they are not deemed a medical specialty in Brazil and are not included in the eight week trainings that introduce SUS practitioners to integrative practices, even though AM can be legally included in SUS. They are largely not included since becoming a medical specialty and fitting the practice into an eight

week training would affect the degree of control AM practioners had over what care was offered and how it was offered, due to the practical limitations of distilling an entire form of medicine into a two month course. AM has been gaining more visibility with SUS physicians, however.

The "normalization" of integrative health practice and use or the appropriation of scientific language and structures has allowed many "alternative" forms to not only compete as legitimate alternatives but also sidestep political and cultural associations that are considered deviant or undesirable by reigning power structures. Adams discusses this in her work on Tibetan Medicine and the use of science to not only act as an exemplary social benefit of the Chinese modernizing project but also as a politically safe repository for Tibetan culture. By emphasizing science, Tibetan physicians could avoid the politically unsafe associations with religion, which were considered an obstacle to Chinese modernization. This emphasis was not unproblematic, however, since it created an artificial/arbitrary separation between Buddhism and Tibetan culture and raised contestations in the understanding of the physical human organization, patient care and the manufacture of medication (Adams 2001).

One movement to integrate traditional systems is through evaluating them in allopathic medical trails "*isolating the medications from the context in which practitioners understand and use them*" (Leslie 1980). Using the "gold standard" (randomized clinical control trials) and the universal adoption of *Good Manufacturing Practices* (GMP) have been a way to evaluate the efficacy and validity of integrative medical remedies (Craig 2011). Yet potency is based solely on the quality of the ingredients and correct processing of the materials, which other practitioners argue is a doomed enterprise given the individualized nature of integrative health treatments (Adams 2001). Problems with making alternative medical models self-evident on an empirical basis arise especially in the distinctions between intellectually and experientially understood and

transmitted knowledge (Adams 2001). Conflicting constructs arise since many integrative practitioners do not use the cosmopolitan medical perspective on disease etiology or therapy (Leslie 1980).

Integrative health therapies have not met the challenge for legitimacy lying down, however. Many integrative systems have acted as a medical counter-culture, resisting the practices and truth claims of the dominant biomedical paradigm, and its attending associations with modernity and the West, either overtly or covertly (Saks 1995). The pursuit for available alternatives or resistance can be seen in one of Indian's most prominent figures, Ghandi who critiqued the view of modern medicine and its associated organs as markers of progress. He believed they encouraged dependency, eroded self-control, and ignored the importance of the soul or sprit in healing, focusing on cure rather than prevention (Khan 2006). Western medicine was resisted as a way to free society from the hegemony of the colonial state. "*Science and modernity were considered the syntax of reform and as a grammar of modern power*" (Khan 2006).

3.3 MEDICAL PLURALISM: INTEGRATION OF BIOMEDICINE AND INTEGRATIVE MEDICINE – COOPERATION OR ANNEXATION?

With the expansion of biomedical care access, many scholars were initially puzzled as to why the biomedical health system was not fully replacing indigenous systems. This was largely related to their assumptions underlying patient choice. Benjamin Paul's volume on the public reactions to medical care sought to unravel this conundrum of why the "*dramatic effects of Western measures of prevention or curing illness were not always self evident*" to the public

(Paul 1955). The works in his volume explore the process by which public health professionals could weave in scientific epistemologies and new expectations of healing and prognosis, and transmit biomedical knowledge about health and healthcare to populations with non-biomedical means of coping with disease and prevention. The beginning of investigations into patient's health seeking behavior began with the question and effort to understand "*how does culture affect perception, communication, and the processes of alternating health habits*" (Paul 1955).

The impulse underlying Paul's investigation spread as integrative health services grew in popularity capturing the attention of academics and national health systems alike as legislators and insurance providers looked for cost effective nontechnical alternatives to extend healthcare access (Baer 2004). This move suggests a shift from policies of uncompromising marginalization to governing biomedical health systems putting in place policies to "normalize" or standardize integrative health practices (Wahlberg 2007). Growing interest in Integrative medicine (both from consumers and regulators) has deployed various measures of safety and professionalization that have caused a convergence of health systems and the rise of a "new medical pluralism" under the watchful gaze of governing structures to protect the public (Cant and Sharma 1999; Wahlberg 2007). This new pluralism does not mean that health systems are equally valued or that the population has equal access to medical resources, however, and may in fact disguise deeper social and economic inequalities (Broom, et al. 2009).

The mainstreaming and integrating of systems has made integrative practices easier to annex within the biomedical health system. By incorporating integrative practices under the legitimizing forces of the institutions that shape nationalist discourse (Khan 2006), dominate health systems are able to appropriate what Saks (2003) called a medical counter-culture (Saks 2003). As Adams pointed out in her work on Tibetan medicine, this is also a way of initiating

cultural transformation – separating medicine from culture, and health practices from political and cultural resistance to modernizing programs (Adams 2001).

The push to "modernize" is the result of external forces as well as internal ones. Pressures to join the medical market as "legitimate" competitors, gain social or political capital, and the permeation/adoption of biomedical standards of value, safety and efficacy have created an environment in which many integrative health practitioners are eager for science to validate their remedies and practices (Croizier 1968; Shuval 2012). Integrative medical institutions are implementing their own forms of professionalization by creating schools, licensing, certification and registration programs, and at times "integrating" or creating their own structures of legitimacy to avoid becoming mechanisms of surveillance and control (Baer 2004). Organizations like the NCCAM have also resulted in conflicts where "legal theft" of integrative health remedies occurs (Adams 2002b; Baer 2004). Besides reflecting larger social and economic process, scholars have argued that this integrative project is not the utopia it is marketed to be and that the incongruous aspects of values and practices have contributed to an "identity crisis," or a compromise of the health systems' integrity in order to "scientificise" practices. By evaluating integrative health practices by the biomedical standard, integrative medicine is not free from intervention by biomedical entities, at risk for marginalization, and at a disadvantage to compete with conventional systems. This has led anthropologists like Fan and Holiday to explore the processes and outcomes of health traditions as that are entangled in separate yet concurrent systems that attempt to continue to operate while avoiding the coopting decontextualized elements of integrative health practice (Adams and Li 2008; Fan and Holliday 2007; Possmai-Inesedy and Cochraine 2013). AM provides an important example of a modality

that is entangled with the public system yet also strives to prevent their approach from being decontextualized.

3.3.1 Conflicting constructs: modernity and science vs. traditional medical and culture forms and values)

While some have studied integrative medicine as an important lens for examining the "progression" towards "modern" ways of life, others have attempted to break away from linear models of patient choice as "progressive" by investigating other contextual factors involved in medical systems and choice (Crandon 1986; Crandon-Malamud 1991; DeWalt 1977; Young and Garro 1982; Young 1981b). Scholars have studied the coexistence of medical systems because they often reflect greater aspects of social change and the expression of power manifested in the health domain or as Frankenberg put it: "*the continuous and pressing problematic relationships between individuals and groups of differential power [who compete] unequally for resources"* (Frankenberg 1980). Pluralistic settings are an avenue for examining the intersection of particular cultural paradigms and in the case of this research, ontologies of personhood. Integrative medicine for example, often negates the Cartesian mind/body dualism found in biomedical models and despite integration efforts, many "alternative" therapies cannot be easily translated to biomedical discourses or approaches for this reason (Possmai-Inesedy and Cochraine 2013). Disease categories are another example of the difficulty in combining different empirical realities (Adams 2002b; Andrews, et al. 2013; Frankenberg 1980; Singer 2004). The question of whose standard is used to set professional norms for diagnosis, therapy and remedies becomes problematic when trying to make all health systems incommensurable (Fan and Holliday 2007). Fan and Holiday sum up the logic that leads to unequal integration and the

predominance of biomedical values in medical institutions "joining" integrative medicine and biomedicine in the following premises:

> *1) The more scientific, the more effective.*
> *2) MSM [mainstream medicine] is more scientific than TRM [traditional medicine].*
> *3) Therefore, (a) MSM is more effective than TRM, and (b) in the integrative system of TRM and MSM, TRM should be improved according to the MSM standard so as to become more scientific and therefore more effective. (*2007)

Contact with biomedicine has brought into focus conflicts with a globalizing medical "truth" raising questions aboutew who determines truth and efficacy and by what measure (as well as whose outcomes count) (Adams 2002b). This research traces some of these questions into the conflicting values or "truths" other forms of medicine bring to the table. The processes by which integrative medicine can gain legitimacy are also those that can criminalize it if it falls short of the "norm." Practices that are deemed illegitimate are criminalized (often under regulations of licensing to practice) while the ones that are approved, face being coopted. Cooption results in an institutionalized loss of autonomy leading to forms of syncretism or "integration" that reflects a privileging of certain forms of knowledge and values over others. This is also why certain forms of medicine have had mixed cooperation with SUS in integration in Brazil (Adams 2001; Baer 1987 ; Baer 2004).

Federal and private institutions are engaged in the politics of knowledge and truth making. The inclusion of spiritual/magical elements in medical practice becomes a target of investigation and criminalization precisely because these elements remain outside of the biomedical paradigm. State intervention becomes justified on the basis of protecting the patient from practices and concepts that have no scientific explanation and may be harmful or exploitative (Adams 2002b). Integrative health practitioners may be pressured to shed "unscientific" elements of their work in order to become part of the legitimate medical

community. This requires redefining elements that do not fit into the language of science by way of participation in clinical trials or other standardizing testing procedures to prove value (Adams 2002b). Approaches that cannot be translated or measured in an RCT risk being deemed without value. Those that are efficacious, risk being appropriated leading to integrative medical practitioners losing ownership over medical knowledge. Inevitable conflicts arise since integrative health approaches look for underlying imbalances as a root cause for illness while biomedicine isolates and targets the phenomenon as a freestanding condition (Adams 2002b). These dichotomies are complicated in pluralistic settings where patient choice is influenced by a number of contextual factors (Baer 2004).

The discussion of health systems must overcome being casting these systems as totalities and the false grouping of medical traditions that are not as bounded, discrete or uniform as they are often portrayed to be (Adams 2002b). With the push for professionalization, many health systems are attempting to standardize practice but this has not always been the case and variation within systems is inevitable. Biomedicine is not an exception although its emphasis on the continuity of practice, epistemology and ontology with an approach to patient care (that is hegemonic) casts it as a uniform system (Frankenberg 1980; Good 2007). Examples of globalized biomedical standardization of practices are evident in polices such as the *Good Manufacturing Practices* (GMP), which often creates conflicts between biomedical and integrative medical standards for the production, prescription and sale of medications. While biomedical research focuses on the quality and quantity of the remedy, it does so often decontextualized from patient care and the level of individuality involved in integrative medical diagnosis and treatment. Standard operating protocol for biomedical remedies, (like the GMP) creates hierarchies of legitimacy that penetrate local belief and value systems and often

transform traditional knowledge systems in the process (Adams 2001; Adams 2002a; Adams 2002b; Craig 2011). Conflicts over medication and reimbursement for example, are primary barriers to integration of AM in Brazil.

Pushes for professionalization are related to the power of narratives since narratives often moralize recounted events with the added drive to convince audiences to see reality a certain and similar way. Narratives "*reflect sociocultural memberships such as professional status and also reflect the imprints left by institutionalized ideologies" (Mattingly and Garro 2000)*. These narratives are "*links to social power, that professionals draw upon in their claims to knowledge in efforts to construct persuasive narrative scenarios for those who seek their assistance"* (Mattingly and Garro 2000).

Narratives expose other points of disjuncture visible in approaches to patient care and medical training. Approaches to diagnosis are culturally guided processes (Atkinson 1998; Singer 2004). Medical training aims to impart the ability to identify manifestations of "disease" but this training is a cultural construction. Biomedicine identifies disease as a separate entity that can be discovered through the signs and symptoms associated with the particular condition. These discourses of practical reason and experience shape the perception of biomedicine as being "normal" (Atkinson 1998).

Contemporary forms of rationality are designed to maximize efficiency, shaping and restructuring many of the goals, values and responsibilities of health care providers. The use of the medical record, problem oriented patient presentation (learning what to recognize about their patients) models of standardized patients and diagnostic technology are just a few examples of "new" objects of value in the biomedical infrastructure that health care providers must learn to recognize and use (Adams 2007). These structures are socially constructed with their own

cultural and institutional histories that shape how physicians are "cultured" (Adams 2002b; Adams 2007; Lock and Gordon 1988; Lock and Nguyen 2010). The technological imperative has played a role in shaping this relationship as that has become a central feature of biomedicine that dehumanizes the doctor patient relationship, distancing providers from their patients (Adams 2002b)[14].

3.3.2 Navigating pluralistic healthcare settings: patient choice

A wave of scholars in medical pluralism has focused on demythologizing the "objectiveness" of biomedicine and the inevitability of evolving to "rational choice" of an objective medicine. "*The tenacity of biomedical assumptions and practices derives from numerous sources --the efficacy of much of the medical practice, the extensive web of institutions, the political, economic, and personal investments in the current model and the successful response of many physicians to criticism*" (Gordon 1998). Scholars like Lock, Gordon and Nguyen attempted to expose the "*the hidden cultural scaffolding and social processes that shape practice and knowledge"* (Gordon, 1998: 20) in order to show that biomedicine is not an inevitable universal truth devoid of culture or ideology (Gordon 1998). Foucault (1977) identified the separation of biomedicine from the mysticism and magic of previous forms as a leaping point for modernity that posited individuals who ascribed to scientific reality as an autonomous sovereign knower who had the ability to disengage from culture and emotion. Biomedicine perpetuated notions of individuality and

[14] It should be noted here that biomedical physicians *do* have agency even if they are constrained by institutional norms. Just as biomedicine is not the same everywhere, biomedical physicians also reflect a great deal of variety.

freedom making (Gordon 1998) and perhaps this is why explanatory models of patient choice have often made the "Rational Man" axiomatic.

While this chapter has referenced many scholars that examine how health systems have professional boundaries that maintain closure, cohesion and power, scholarship has also examined how these systems interact and have effects on one another (as seen with the internal push for legitimation by many integrative health practices) (Farquhar 1994; Shuval 2012). Patients are the inevitable site of these negotiations and a lens for examining the differences in health care approaches. Berg and Bowker showed how a simple device such as the patient record could produce a patient's body by configuring the body and its history through "rational" reconstructions. The production of a medical record acts as a locus for the exercise of power, and is interwoven with the structure of medical work since it is connected to nursing and laboratory routines, medical technology and health networks (Berg and Bowker 1997). Patients are the battleground for competing organizational logics and regimes of truth, making patient choice an obvious site of interest (Andrews, et al. 2013; Moreira and Palladino 2005). Patient choice also represents a problem for scholars who treat medical pluralism as an inevetible linear march toward biomedical healthcare.

The use of "new" biomedical paradigms is often cast as choosing one way of life over another, yet as many scholars have shown, choice often involves a reorientation where remedies are acceptable within concurrent (and potentially contradictory) health systems (Wolff 1965; Young and Garro 1982). Young and Garro showed that choice was often fluid and more dependent on accessibility than the degree of conceptual consistency (Young and Garro 1982). While the application of modern science to the problems of everyday living and health has been

instrumental in higher life expectancies, it could be characterized as a foreign intervention/ imposition that have mixed receptions (Wolff 1965).

Compliance with biomedical standards can signal an adoption or belief in the efficacy of "Western" measures or simply catalog a response to (institutional) authority. People can enjoy the products of modern medicine without changing their values allowing for the coexistence of incompatible ideas especially in cases where: "*It is easy to enjoy the fruits of an alien civilization, but very difficult to change one's own civilization to produce similar fruits*" (Wolff 1965). Multiple forms of healing and knowledge production can exist in one society (Rasmussen 2001). Understanding how and why people use different system was of particular interest to anthropology during the beginning of medical pluralism as way to understand what it would take to provide the best care, the internal logics that determined choice and to unpack the power embedded in healing practices within which communities develops fluid use of many systems (Rasmussen 2001). Chapter 4 will explore some of these same patterns displayed by AM patients.

Interest in patient choice and cooperation or competition across lines has also transformed the foci of medical pluralism where medical choice was not just a matter of healthcare but also a demonstration of *boundary work.* Both physicians and patients engage in *boundary crossing* or *boundary work* in order to transition between different sets of professional and epistemological axioms. [15] These borders demarcate identity, epistemology, and cognitive,

[15] "*The biomedical paradigm is founded on "the assumption that all disease is generated by specific etiological agents such as bacteria, viruses, parasites, genetic malformations, or internal chemical imbalances" (Berliner, 1984, p. 30).* The perspective of biomedicine is characterized by rationality, objectivity, positivism, determinism, universalism, and linearity, whereas its methods emphasize logic, controls, measurement, and deduction (Shuval, 2012).

organizational and social elements. Physicians practicing multiple forms of medicine or working with physicians who have different professional identities engage in blending these practices through mechanisms to establish (or prove) legitimacy (Farquhar 1994; Shuval 2012). Border crossing has wider implications for bridging medical borders between biomedicine and integrative medicine as well as between different national, ethnic, religious and political groups (Keshet and Popper-Giveon 2013). Examples of this can be seen in Keshet and Popper-Giveon's work investigating how herbal medicine was used as boundary objects by Arab and Jewish physicians. By emphasizing common treatments, practices and practitioners, herbal medicine became a boundary object that enabled collaboration and mediation between diverse (and polarized) political, ethnic and religious identities (2013).

The individualization of health, risk, choice and responsibility has renewed interest in patient decision-making models, which were originally popular during the advent of work in medical pluralism (Possmai-Inesedy and Cochraine 2013). Patient choice has been continually relevant for cultural competence training striving to break out of generalizations about beliefs by examining intra and inter cultural variation. This requires moving on from models of individual choice to models that consider the structural and cultural factors together in choice. This is one of the reasons why ethnomedicine is biomedically relevant, especially in the wake of large global immigration (Orr, 2012).

Anthropologists have examined the internal logics of resort within particular cultures attributing resort to a number of different factors. Availability of medical resources, loyalty to local forms (more so illness rather than remedies) against the backdrop of biomedicine and technology have fascinated and confounded scholars alike. Many of these studies argued that available options are ordered on the basis of severity, illness types, and progress with any

particular form (Colson 1971; Garro 1998; Myntti 1988; Schwartz 1969). Availability and efficacy have been key aspect of examining choice in pluralistic contexts with varying emphasis on the historical and political economic structural forces constrains/determines the differential use of medical resources. These have taken forms such as: folk *dichotomy, efficacy-testing, shotgun therapy, chronic versus acute, relative wealth, relative acculturation and innovation theory (Colson 1971).* Yet, these models have struggled to be generalizable.

Folk dichotomy hypotheses used by scholars such as Foster (1958), Erasmus (1952) and Simmons (1955) examined choice situating "modern" and "indigenous" medical systems opposed to one another. Choice between systems is dictated by whether the illness is supernatural or natural in origin. (This assumes that natural and supernatural are neatly divisible). Others (Torey 1968; Erasmus 1952 and Schwartz 1969) examined the idea of *efficacy* and choice based on the belief that a particular illness will respond to a specific form of therapy (Colson 1971). For severe and enduring illness, several scholars (Hsu 1955; Ubel 1966; Madsen 1960) have discussed the exhaustive use of every possible resource that is available as a strategy for achieving a cure.

Shotgun models were used as a way to explain why patients often used multiple forms of therapy simultaneously (with or without rank ordering health resources). *Chronic vs. acute* took this analysis in a similar direction, examining how use can be delineated on the nature of the disorder (chronic vs. acute), suggesting alternative providers are better suited for nonfatal chronic conditions (Colson 1971; Kleinman 1980a; Sirois and Purc-Stephenson 2008). Availability (economic and geographic constraints and contexts) also played a role in patient choice models (Colson 1971; Myntti 1988). When illness was not serious, patients tended to take the least expensive course of action, and exhausted increasingly expensive options if necessary.

Cost became less important if the severity of the illness increased and often where biomedicine becomes desirable. [16] While these models of choice have since become dated, they were often referenced in some form or another by biomedical physicians in trying to explain why patients were opting out of SUS care.

Relative acculturation theory and *innovation theory* made efforts to better examine intercultural variation in choice with mixed results. The identification of mixed health practices changed the trajectory of hierarchy of resort literature that struggled to create models that were applicable in multiple settings. DeWalt's work in Mexico showed that patients incorporated "new" health systems and resources, in a mixed pattern of resort that did not necessarily follow a linear continuum of "progress" toward biomedical resources (DeWalt 1977). Young also attempted to explain mixed medical strategies through his work in Mexico by creating a decision-making model that focused on the alternatives available to patients, how they selected the alternatives and what was involved in the decision making process (Young 1981b). The underlying assumption in his work was that there was a " *generally shared, natural decision-making process for the treatment of illness that we can in fact discover" (Young 1981b)*. Young argued that this assumption was justified since illness is and always has been a fact of life for humanity and one that people have had to create (standardized) strategies to manage. Young asserted that the logic underlying his decision-making model was reflected in the fact that most people exhausted an alternative before moving on to another, and moved from one alternative to the next for many of the same reasons ranking the health systems available to them (Young 1981b).

[16] Garro addressed this specifically naming four criteria in choice

Garro's work further developed the literature of patient choice asserting that decision-making is not simply based on a utilitarian calculus. Decision making models evolved out of predicting treatment accounts to models that also included "*the jointly cultural, personal, social, and cognitive constructive processes through which meaning is conferred upon the occurrence of illness*" (Garro 1998).

Crandon-Malamud's work embodied this push for an expanded patient choice model attempting to include greater associations of choice with identity and status. She did not object to a cultural reason approach but like Allan Young, challenged several assumptions underpinning rational decision models. Many patient decision models assumed that choice was voluntary, rational and personal, overlooking the wider context and the social and economic constraints therein. Models like these also assumed that informants could report on their healthcare decisions according to those criteria. Allan Young specifically critiques explanatory models using the "Rational Man" as its foundation, arguing that while these models functioned, they were not universal and at times contained problematic axioms that made them inappropriate or impossible to apply in other settings (Young 1981a; Young 1982).

Crandon-Malamud acknowledged the economic and social considerations, which affected patients' perceptions of medical efficacy but took a descriptive method in order to illuminate the patterns of care and cultural knowledge about illness/order of the society in question. Crandon-Malamud argued that participation was not a matter of all or nothing (rational) choice but a more nuanced decision between a variety of systems. She connected identity, patient choice and group membership as related to status and trust. The use of a given health systems was not only a way to become well but also a way to affect how patients were perceived by their community. Crandon-Malamud showed that medical choice has implications for status, wealth or as a way to

make statements about group affiliations (Crandon-Malamud 1991). "*In this medical dialogue, what people say about their social world through the idiom of medicine are statements about political and economic realities, and the meaning of ethnic relations*" (Crandon 1986). Medical participation has the power to restructure social relations outside of the medical context as well (Mattingly & Garro 2000).

The importance of medical dialogue or narrative also held a prominent role in Mattingly and Garro's work. Narrative could be used to illuminate otherwise unseen practices and experiences involved in illness (Mattingly and Garro 2000). Narrative is not only a way to make sense of experience it is also a culturally constructed process tied to identity with the power to shape conduct: "*Powerful stories can shape future actions in decisive ways, and this only increases the complex and intertwines relations between telling stories and taking actions*" (Mattingly and Garro 2000). While some later scholarship has captured more nuanced aspects of patient choice, it has not fully developed the idea that medical participation was also related to identity, status and a means to makes political statements in changing cultural landscapes (Adams 1998; Adams 2001; Adams 2002a; Crandon-Malamud 1991; Croizier 1968; Janes 1995; Janes 1999; Janzen 1978; Keshet and Popper-Giveon 2013).

3.4 CONCLUSION

With globalization, medical movements are becoming more available on a worldwide scale. Both governments and citizens have developed ways of strategically positioning themselves in this global context. Some of these medical movements are able to enter into spaces and functions previously held by the state by mobilizing national support for health interests and international

support through translocal solidarities – groups united around campaigns of illness and rights - in what could arguably be called transnational biosocialities or "global geographies"(Biehl 2007).

> In defense of their rights, they [patient] created a syntax that combined "modern values" such as autonomy and citizenship with "traditional values" such as community, religiosity, and solidarity, learning to establish productive partnerships with neoliberalizing governments (Biehl 2007).

Through making healthcare an issue of social justice, and a right of the biological citizen, patients are able to bargain for services to ameliorate inequalities by demanding that the state fulfill its mandated biopolitical obligations to the citizenry (Biehl 2007; Petryna 2004a). This research examines how ontologies of personhood introduced through AM and SUS not only effect what patients demand from the state but how these ontologies create different forms of biocitizenship adopted and incorporated by patients through their medical choices.

Through Brazil's 1988 construction and continuation of the state healthcare program, patients have become the locus of choice as they are increasingly positioned as individual autonomous agents responsible for their own health, negotiating their positions between medical systems. Brazilian citizenship is linked to the right to health and SUS, which extended the reach of government into the lives of the citizens under the rhetoric of safety, security and responsible living. Just as patient choice is a way of making statements about the self and about membership (Crandon, 1986), the provision of care allows governments to create an imagination of the state that is both modern and democratic legitimating their administration. *"Through specific sets of metaphors and practice, states represent themselves as reified entities with particular spatial properties. By doing so they help secure their legitimacy, to naturalize their authority and to represent themselves as superior to, and encompassing of, other institutions and centers of power (Ferguson & Gupta, 2002, p. 982).*

Brazil's universal healthcare system was part of one such state project to usher in a new era of democracy and to create and disseminate a "new" set of democratic values (Burlanty 2000).Yet patients are able to exercise agency through negotiating with states= healthcare agents, mixing types of care or opting out of public healthcare entirely. These choices have implications for how patients engage with medical resources as well as the State itself. In an environment with multiple medical systems with their own values and ideologies, understanding the influence of these alternatives and how patients navigate choice remains an important project for anthropologists. I argue that understanding the ontologies of personhood put forth by medical modalities and how these ontologies inform the expectations for the rights and responsibilities of biocitizens is critical for understanding patient choice.

> As Heath, Rapp and Taussig (2002) have pointed out, citizenship in the contemporary age of biomedicine is manifested in a range of struggles over individual identities, forms of collectivization, demands for recognition, access to knowledge and claims to expertise. It is creating new spaces of public dispute about the minutiae of bodily experiences and their ethical implications - a politics of embodied or somatic individuals. It is generating new objects of contestation, not least those concerning the respective powers and responsibilities of public bodies, private corporations, health providers and insurers and individuals themselves (Rose and Novas 2005).

The right to health inscribed in SUS was an important political project for Brazil and its creation of the "new Brazilian biocitizen" as the nation transitioned out of authoritarian rule. The inclusion of integrative healthcare policies is an extension of this project expanding access, subsuming competing modalities and ontologies of personhood that underpin them (2008). This research shows how patients who participate in non-SUS care such as AM are influenced by the ontologies of personhood that underpin unconventional forms of care and how these ontologies influence patient choices as they reject or reimagine biocitizenship.

4.0 CHAPTER 2: METHODS AND RESEARCH SETTING

4.1 RESEARCH SETTING

This research came out of an apparent paradox: Brazilian patients who did not reject biomedicine were still choosing other forms of care like Anthroposophic Medicine that were more expensive, less accessible and less well known when quality biomedical care was available through Brazil's Unified Healthcare System (*O Sistema Único de Saúde SUS)*. SUS came out of Brazil's transition back to a democracy in the 1980s. State sponsored healthcare for all was an important milestone in this transition, reshaping the relationship between citizens and the state. When examining why patients would opt out of this healthcare system, this research considered of this relationship between citizens and the State and the role of SUS and biomedical physicians played in shaping biocitizenship.

Instead of approaching choice in a pluralistic healthcare setting as one based on cost or access for example, this research examines the choice of patients to opt out of SUS care as a choice that enables them to opt out of ontologies of personhood created through state sponsored biomedical care that assumes a specific vision of the "new Brazilian biocitizen." This research posits choice as influenced by patients desire to access and participate in other forms of medicine with non-conventional ontologies of personhood that contribute to non-conventional biocitizenship. In order to show why Brazil, SUS and Anthroposophic Medicine have been

chosen for this research, this chapter includes an examination of the Brazilian healthcare context that selectively includes AM as well as a description of the field site.

4.1.1 Choosing the healthcare context: the importance of the Brazilian context and SUS

The focus for this research is not what SUS has accomplished in terms of health outcomes, expansion of access or its number of healthcare teams. Brazil's healthcare system was chosen because of its nature as a political project designed to usher in a new era of democratization – a means and marker of political and cultural transformation. The health systems that preceded SUS were a reflection of the relationship between citizens and the state and a solidification of who "counted" or remained marginal or unprotected under the state. The movement of the Brazilian government and proponents of Sanitary reform to focus on inclusion of all Brazilians in a new democratic Brazil was designed to address the holes in healthcare, inequality and the political issues of the past regimes. The right to health for all Brazilians became a way to bridge the gap between rural and urban regional disparities as well as across socioeconomic lines. The promise of equal access to health was a key part of the promise of equal access to citizenship.

Providing free biomedical care came with implicit and explicit understandings of what the state and the citizen were entitled to and responsible for solidifying a specific relationship between citizens and their state. Encapsulated in this relationship was an understanding of who the new Brazilian citizen was in the "new" Brazil. How people understand themselves as people (personhood) and as citizens was heavily shaped by this amalgamation of a specific form of healthcare (and way of viewing the self/body) and a set of political responsibilities and entitlements. The bio-medicalization of life and public policy opened avenues for citizens to demand services based on their bio value or biolegitimacy while it also enabled the state to create

and represent itself as a new biopolitical regime. SUS physicians have the ability to produce a biomedical personhood that orients the citizen in this new regime. Patients reproduce this vision of the citizen by participation in the system.

4.1.2 Context for the creation of SUS and the Brazilian biocitizen

Since this project explicitly deals how healthcare choice may be affected by a desire to opt out of with state visions of the citizen, it was necessary to begin with a state sponsored public healthcare system that is associated with biocitizenship. Through the marriage of democratic reform to healthcare reform, Brazil marked its transition from a military dictatorship to a democracy, in part by creating a nationalized biomedical public healthcare system with strong explicit ties between the state and biomedicine. The constitution of 1988 states that access to health care is a matter of equal citizenship. Until the 1960s, Brazil relied on its social security system to pay healthcare costs. Because social security was arranged between employers and employees, social security benefits were available only to laborers employed within the formal economy; and only half of the population met this criterion leaving a large section of the population without coverage (Fleury 2001). With the military regime and the centralization of power that followed in the 1960-1970s, healthcare began to move to a universal model.

The end of the military regime in the 1980s, along with the social security crisis, brought some attempts to regulate the expanding private sector and make healthcare accessible for all Brazilian citizens (Lobato 2000). The first wave of reform and the beginning of the "Sanitary Reform" aimed to establish criteria for allowing the private sector to operate in the name of government (Lobato and Burlanty 2000). During this time, the Health Movement emerged. Composed of intellectuals and health professionals, this movement aimed to "democratize" the

healthcare system by abolishing inequality within the health sector. The Health Movement blamed the military regime for the poor state of healthcare. The provision of universal healthcare as a right of all citizens was the Health Movement's answer to bring healthcare into the emerging democracy. Healthcare reform aimed to address several problems within the system:

1. Broaden the financial base for health care beyond the social security funds
2. To put the public sector in charge of regulating the private sector
3. To transfer authority and resources from the central government to the state and municipal levels
4. Include social institutions in forming institutions and policymaking (Lobato and Burlanty 2000).

The reform called for the decentralization of the provision of healthcare from its previously centralized model. Decentralization unfolded in three phases. The first phase was the *Integrated Health Activities phases (AIH),* characterized by budgetary tightening, increased use of services and facilities held by MPAS and conversion of many inpatient cases and procedures to outpatient one. The second phase, the *Unified and Decentralized Health System or SUDS,* marked the beginning of transferring staff and facilities to state control and the removal of social security institutions from medical control (Cruz-Saco 1988). The third and final phase was the *Single (or Unified) Health System (SUS),* which was the complete transfer of resources and management to the municipalities provided that they met certain criteria or stages of management (Lobato and Burlanty 2000). SUS was governed by a legal framework consisting of the Health Organization Laws, the state and federal constitutions and the (municipal) Organization Laws. Within this legal framework, the Health Organization Law governed the condition for health promotion, the protection of care and the basic mechanisms for managing the healthcare system. It also regulated the resources provided at each level of governance (Lobato and Burlanty 2000).

The decentralization of healthcare aimed to relieve the federal government of trying to run, maintain, write policy and oversee the healthcare system at the same time in order to prevent duplication or holes in service. In a decentralized system, each level of government was supposed to have defined responsibilities to encourage efficiency. The federal government was supposed to develop national health policy, control regulation (overseeing public/private relations and authority) and provide technical and financial support to the state and the municipalities. The state was then responsible for governing the regional healthcare network and providing technical and financial support to the municipalities. The municipalities, supported by the federal and state governments, were tasked with the actual provision of healthcare services and health planning. Within this system, municipalities would ideally be able to tailor the services they provided to the needs of the populations they served (Lobato and Burlanty 2000).

SUS emerged from a number of attempts at creating a healthcare system and was designed to address perceived weaknesses in earlier iterations of the fragmented healthcare system, including excessive centralization and unequal or limited distributions of services and primary care in certain areas of the country. While the process is one of continual struggle to achieve true universal access, the healthcare system has expanded its capacity significantly in the last 30 years. The number of outpatient healthcare facilities alone has tripled from 1981 to 2009, while the number of hospitals has remained fairly stable, and the number of hospital beds slightly declined as more emphasis was placed on primary care and family health teams who make house calls (Gragnolati, et al. 2013). These teams extended the reach of the healthcare system significantly from its original 4,000 teams at the beginning of sanitary reform to 31,600 by 2010. SUS has also managed to expand the volume and variety of services provided to citizens especially in services like dental consultations and integrative healthcare practices. While

disparities exist in accessing diagnostic, preventative and curative services, there has been a significant reduction in unmet need as well as the number of patients who cannot access care due to financial constraints. SUS has also contributed to advancements in life expectancy and reduced infant and child morality in particularly (Gragnolati, et al. 2013).

Some of what SUS has accomplished is less easily quantified. Establishing a right to healthcare was designed to operationalize democratic reform as well as demarcate it. The formation of health councils at every level of government was designed to create societal participation in the healthcare system. "My" neighborhood health post for example, had a monthly meeting that was announced on large poster above the entrance inviting residents to discuss their concerns with these councils. (I never encountered a single patient or physician who referenced these meetings, however.) Access and quality are other aspects of the health care system that is more difficult to measure since it also depends on waiting times for appointments (especially with specialists), diagnostic tests and treatments, which vary regionally.

4.2 SUS IN FLORIANÓPOLIS: THE RESEARCH SITE

Because there is such a variety in the services provided, the resources allocated to provide those services and the technical capacity and scale of each municipality, satisfaction with SUS services is equally variable. Florianópolis alone has 52 municipalities. These municipalities heavily contrast one another in income levels and in several cases culturally. *The Costa da Lagoa* , for example, is a *bairro* only reachable by boat (or a *very* long hike) and is home to residents who are often identified as "more traditional," "*manezinho*" or of Azorean descent.

Florianópolis has a large concentration of resources both in terms of financial support and personnel. SUS generally works quite well in Florianópolis compared to many other areas of the country. Both physicians and patients referenced this repeatedly. It is precisely due to the successful implementation and functioning of SUS that Florianópolis was chosen as the primary research site for this project. By minimizing the influence of variables such cost, access and quality care from the mix, there was a greater opportunity to clarify what other variables are involved in patient choice

Originally a port city name after Brazilian president Floriano Peixoto after revolutionaries failed to take over the island, Florianópolis transitioned from a small port city to a permanent destination for Ukrainian, Italian, German and particularly Azorean immigrants seeking new lives in the new world. Areas of the island still maintain strong ties with European homelands with residents still making *renda do bilro* (bobbin lace) in traditional ways some of which have been forgotten in Portugal. The everyday beauty of Florianópolis is captured in the traditions and untouched nature that longtime residents have fought to preserve as developers and outsiders flock to their shores in search of a high quality of life.

Located off the shore of the second to most southern states in Brazil, Florianópolis is often thought of as a popular vacation spot and an area of immense beauty and wealth. The island is home to many summerhouses of affluent Brazilians and Argentinians who visit during the summer months when the island's population more than doubles with beach going visitors. While outsiders and permanent residents alike cast Florianópolis in idyllic terms, the year-round reality of the entirety of Florianópolis is less opulent. Summer months are an exception in the rhythm of the island, marked by a mass exodus of residents fleeing the impossible traffic, price hikes in everything from gasoline to coffee, and the waves of out of town vacationers. Residents

have a mixed relationship with visitors since tourism provides an important source of income for residents selling goods and renting houses, while also contributing to shortages of local goods, traffic and crowds of beach seeking tourists who are not always on their best behavior.

The everyday reality of Florianópolis for residents is markedly different from life during summer holidays. During the nine or so off season months, I observed the island taking on a sleepier and simpler atmosphere, where students still hitchhiked to class, the traditional artisan fishermen worked on closed beaches with neighborhood residents to catch schools of *Tainha* with wood canoes and handmade nets, and the public transit buses were occasionally joined on the side of the road by residents on horses.

Florianópolis has changed dramatically in the last 20 years with its population doubling. The island and particularly the *bairro* where I lived and in which The Clinic is located, is home to what many would categorize as new age or alternative movements although herbal remedies, teas and homeopathy are already relatively common in Brazil. One can find organic markets, vegetarian cuisines and shops, health food stores and pharmacies that offer many traditional remedies, herbs, and even anthroposophic medical products although to a less extent. It was not uncommon to find homeopathic remedies, bee pollen, essential oils and other like products at the local drug store. For a fee, some stores even delivered via motorbike to the house. The interest in other forms of health care is present in both patients and the medical establishment. The Commission for Practices in Integrative Health was made up of health professionals who often offered mini courses on everything from acupuncture to herbalism raising awareness about and meeting a growing demand for integrative healthcare at public healthcare posts.

4.2.1 Choosing the field site

Florianópolis was chosen as the field site for several reasons. With a population of nearly 480,000 people, the island city provided a clearly demarcated area for research that was less effected by the unrest leading up to President Dilma's impeachment. Tensions had escalated nationally between the increasingly unpopular government and its citizens during preparations for the World Cup. The national protests and violent clashes between demonstrators and police made it clear a field site outside of São Paulo with an AM nucleus would be needed. This was made inescapably apparent in 2013, as anti government manifestations were injected with new vigor after the government attempted to raise public transportation costs to pay for the 12 stadiums they planned to construct for the 2014 World Cup tournament. While these protests were concentrated in larger cities, they were nevertheless an omnipresent reality throughout Brazil.

While protests did arrive in Florianópolis – the most notable of which resulted in 30,000 people shutting down the only working bridge off of the island – protests were rarely dangerous. Banks, bus drivers, health care post physicians and nurses, university workers and trash workers did repeatedly strike, the most disruptive of which to the project was a four month strike by university administrators. While these strikes made obtaining the required permits and paperwork a lengthly and at times nearly impossible process, they did not pose a threat to safety.

Florianópolis has one of the highest human development indexes in the country, ranking third highest among the 5,565 Brazilian municipalities. Public education and healthcare in the area are consistently cited as among the best in the country, making it an appropriate location to examine why patients are opting out of biomedical care for reasons other than concerns over quality or cost and access (PNUD, et al. 2018). By examining the public system in a setting such

as Florianópolis, I minimized the influence of cost, quality and access variables that are implicated in patient choices.

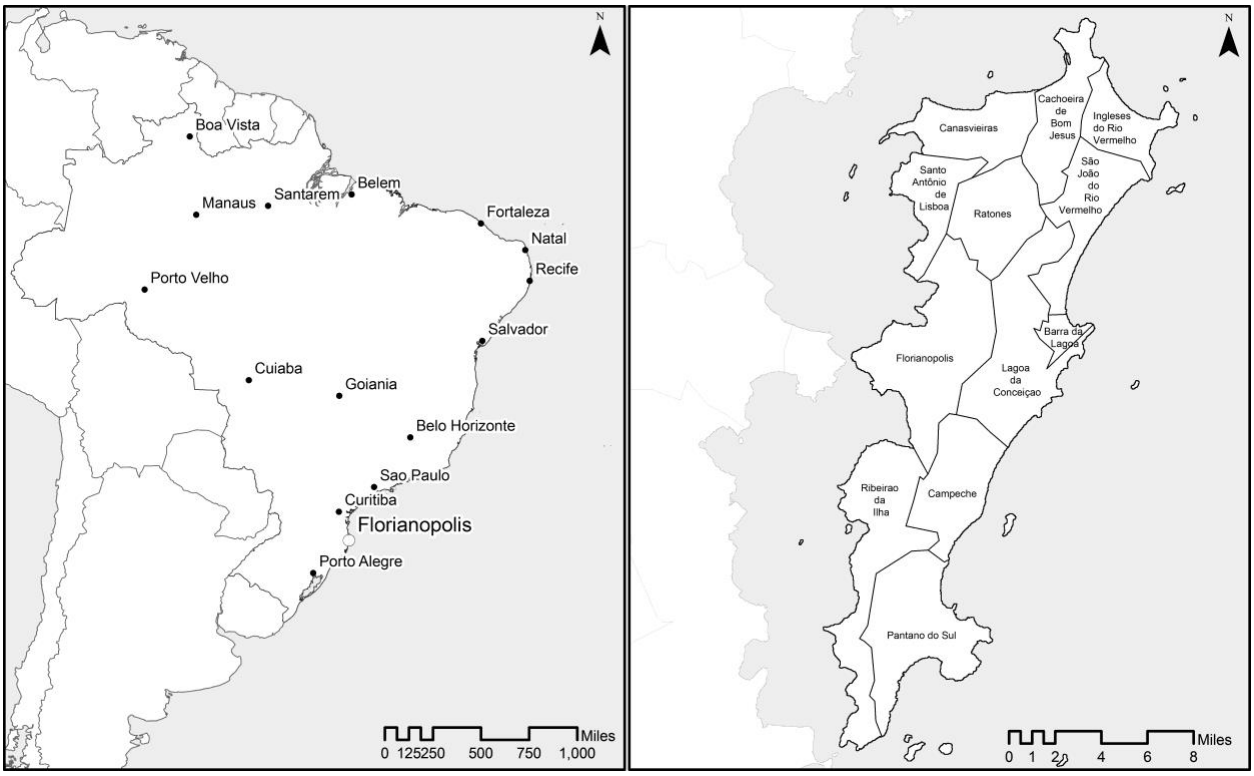

Figure 1. Location of Florianópolis (left) and districts in the island (right)

4.2.2 Choosing the case study: why Anthroposophic Medicine

Due to its clear emphasis on respect for individual freedom and autonomy, mixed used of allopathic, homeopathic and anthroposophic remedies and principles, and non-conventional ontology of personhood, AM was a pertinent case study to compare the healthcare choices of AM and strictly public healthcare system patients. Brazil also has one of the strongest anthroposophic communities in the world outside of Switzerland and Germany, where it was

started with Rudolf Steiner and Dr. Ita Wegman in the 1920's as a way to expand the approach to biomedicine through a holistic approach to the person. The placement, organization and lobbying power of several of the nuclei of anthroposophic medicine in Brazil has also led to its official inclusion in the national healthcare system and a robust presence in the public healthcare system in *certain* cities in Brazil. For a detailed description of anthroposiphic medicine, see Chapter 4.

Brazil has three major nuclei of anthroposophy within the country: São Paulo, Minas Gerais (Juiz de Fora and Belo Horizonte) and Santa Caterina (Florianópolis). Florianópolis has several Waldorf schools (anthroposophical based primary and secondary education), Sagres - a center for education and training in various anthroposophic courses including the medical courses - and a *therapueticum*, which for zoning reasons can no longer officially be called a clinic although throughout this dissertation will be referred to as The Clinic. The Clinic "compound" includes Sagres, a café that serves organic and biodynamic food, and a number of meeting rooms and buildings that host everything from community music events to lectures and a variety of anthroposophic trainings in art therapy, music therapy, biographic counseling, medical training and numerous short courses. Having both training and clinical and social practices hosted in one area facilitated opportunities for participant observation throughout the community, networking and recruitment. The concentration of anthroposophic activities and participants made it an effective location to see how AM personhood was produced and reproduced by practitioners and patients alike.

It is important to note, while anthroposophy has a strong presence in Florianópolis, and has been included in the national public health law as a integrative or complementary healthcare form, AM has a limited presence in public healthcare posts in the area. Some anthroposophic doctors have public and private practices, but the work they do inside the public system is not

specifically marked as anthroposophic. They are limited by appointment times and the inability to prescribe anthroposophic medicines, which are expensive and are not included in the healthcare system and are therefore, not reimbursable. AM doctors find ways around this prescribing homeopathic and herbal remedies as well, which are often much cheaper or covered by SUS.

The relative absence of AM in the public system compared to areas in São Paulo, Belo Horizonte and Juiz de Fora is particularly important to understanding healthcare choice and why Florianópolis was chosen for this project. Individuals seeking AM must do so outside of the public system at additional travel time and cost to themselves. There are several private anthroposophic practices across the island with the largest concentration at the clinic. In addition, Florianópolis' healthcare system functions well compared to other parts of the country as several Brazilian doctors at conferences both inside and outside of Brazil have insisted should be noted. Many Brazilians coming to the island for education, notably students who become physicians, decide to stay in the area after they complete their education, leading to a high concentration of professionals in the area who offer services that are not available in other areas. Several Brazilians I met with at a rehabilitation center for critically physically impaired patients in the public system traveled long distances from the mainland to access these services. The unique quality of healthcare in a place like Florianópolis aided the project by minimizing the influence of access and quality variables.

4.2.3 Preliminary research in Florianópolis

In 2013, I conducted preliminary research in Florianópolis interviewing several AM physicians around the history of AM in the and at The Clinic. After speaking with these physicians and

meeting with founding clinic members and the director of the clinic as well as one of the instructors for the medical course, it was clear that the staff was receptive to the project and that site would be appropriate for research activities. One of the physicians helped me find lodging with an anthroposophic therapist who works with special needs adolescents out of her home in the same *bairro* as the clinic about a 15 min bus ride away. I was also able to make several connections to the anthroposophic community in Brazil through my own history as a Waldorf student (anthroposophic based education) for grade school. While anthroposophic education does not explicitly teach students about anthroposophy and it had been many years since I had been enrolled in a Waldorf school, it did bring me into contact with the individuals such as the head of the *Physicians Association for Anthroposophic Medicine*, and the coordinator for anthroposophic medical education in the U.S. These connections allowed for initial entry into the anthroposophic medical community where I was able to build a foundational understanding of the anthroposophic approach to health, illness and patient care.

4.2.4 Description of the Anthroposophic Clinic Site

The Clinic, founded approximately 15 years ago, is in an expanding section of the *bairro*. Primarily a residential neighborhood, it is located at the end of a small quiet street close to a Waldorf preschool. Over time, the area was rezoned under the auspices of a new mayor, and The Clinic became a *therapueticum* or consortium. The building itself is inviting and open, with a short walkway to the entrance. The glass door entrance, which is nearly always open except during the lunch hour, very cold weather, or closing time, is framed by walls of glass windows trimmed in a red ocher wood and decorated with wax paper stars. The door opens into a small waiting room with a little table for children and a 3.5 ft. tall wrap around wooden reception

counter that curves along the back corner of the room. This counter is always staffed by one receptionist who does all the booking for the four resident physicians, as well as organizing the billing and coordinating the various rooms in use for the additional anthroposophic practitioners who work there. She also greets all of the incoming patients, readies all of the records for the physicians, notifies practitioners when their patients have arrived and answers an impossible number of phones while always making sure a thermos of hot tea is in the waiting room next to a stack of clean espresso cups. While The Clinic had two receptionists during my time there (one that quit three months in), they both, particularly the second, were integral to the project, helping me schedule interviews with practitioners, introducing me to patients, and assisting with some initial language kinks at the beginning of research.

Across from the reception area on the left side of the room, is a double set of green leather chairs put together like a bench in a square around a carved table and intricately crocheted white star rug. This table becomes a source of great entertainment for children who like to push marbles around the maze carved into the top of the table. During my time recruiting patients in The Clinic, I spent the day in one of these chairs casually chatting with patients as they waited, and available to be introduced to patients as they finished their visits and were walked out by their physician.

The waiting room opens onto a back hallway that is joined by a set of glass double doors on the left and a wooden staircase to the second floor where all the patients consult with their doctors or meetings are held, on the right. This hall is also connected to a small kitchen and eating area where staff can reheat food or make coffee and tea. The double doors from the hall lead to a little covered porch that looks out onto the garden and the various meetings rooms of Sagres. This porch has a large round table and several chairs sheltered from the sun and the rain.

I conducted the majority of interviews on the porch since it was onsite, could be used at a moment's notice, and the doors could be closed for privacy.

The second floor of The Clinic has six rooms along a hallway that parallels the one on the first floor. These rooms rotate in use since various practitioners use the space depending on the time of day and day of the week. I met with practitioners in four of these rooms for interviewing, planning and on several occasions as a patient after becoming ill. One of these was a larger meeting room with large windows that could be opened for a breeze as a reprieve from the heat. While each room was different, they all had the basics of an examination room - an examination table and a desk with at least two chairs. Rooms were painted in muted salmon tones with furniture and curtains that created a homey rather than clinical atmosphere. Doctors themselves did wear white coats (although not all and not all the time). When patients arrived, doctors often peaked out from windows on the second floor that overlooked the waiting room, or walked down the stairs to reception walking the next patient up again.

The flowing of patients and physicians in and out accompanied by the cheerful chatter of the receptionist created a both tranquil and dynamic atmosphere in the clinic. Nearly everything is constructed out of wood or glass with open entrances and windows allowing daylight and a pleasant cross breeze to pass throughout The Clinic throughout the whole day. The Clinic is essentially surrounded by Sagres, backed up by a garden complete with small walking paths and boardwalks to other buildings and several small tables and stools shaded by patches of trees. The garden space is a favorite for family members waiting for patients during their visit especially if they have young children, who are endlessly entertained by a little fountain that trickles water from one basin to the next in a small hill, and several large lizards that live under one of the boardwalk paths. Huge bromeliads next to the porch bloom and trap water in their colorful cups,

which also attract hummingbirds, another favorite of garden visitors. The garden also provides an additional space for people attending workshops, trainings or symposia at Sagres, where they can talk, drink a coffee, or eat lunch outside when the weather is nice and the mosquitos have not emerged yet. Additional covered areas with tables and benches surrounding the garden provide spaces for people eating lunch at the Sagres cafe or enjoying coffee and snack break during courses.

A boardwalk surrounds the café with additional sitting places around a small fountain and a one-room area that acts as the newly opened bookstore. The store is particularly important for providing materials for purchase for anthroposophic courses. Since many of the materials are not in presses with large circulation, the store enables visitors to access a range of anthroposophic materials on education, health, agriculture and much more. Between the café and the bookstore on the second floor is a series of dormitory rooms to rent for people coming for courses from afar. These rooms are a cost effective alternative to hotels for many visitors who spend full days training and do not want to have to navigate commuting back and forth even for several residents who lived on the far north end of the island.

Sagres and the clinic are two separate entities, but because they share the same grounds and congregating spaces, the two blend into a larger complex of wood and glass buildings tucked into nature. The space is reminiscent of the popular cinematic depictions of the "Shire" in Hamilton-Waikato, New Zealand, from the Tolkien films. The neighborhood it is set in is both beautiful and quiet yet the compound is another step removed from outside world. The contrast never ceased to amaze new visitors, who often remarked how serene and picturesque the spaces and The Clinic itself was.

4.2.5 Descriptions of Public Health post sites

This research largely took place outside of public health posts for a variety of reasons stemming from municipal regulations and liability concerns. I was able to meet several SUS physicians at their health post, however, for interviews. Public health posts and hospitals were a deep contrast from The Clinic. Often small and tucked into surrounding neighborhoods, health posts still remained their own unobtrusive contrast to the surrounding city, especially large metropolitan areas such as the city center, or the numerous apartment and office buildings on the north side of the land. Most of the work with SUS practitioners and patients was conducted offsite since physicians were often quite busy during office hours and unable to see an anthropologist in the middle of a workday. Other times, SUS physicians were on strike and so interviews needed to take place offsite. Patients were recruited offsite due to IRB and CEP recommendations. The layout and makeup of the posts were all different, some with reception desks immediately to the right with waiting rooms lined with rows of bus terminal like seating. Others had a reception desk in the middle of the waiting room and seating around it. Each post had its own unique set up and arrangement. Some were dark and quiet, others bustling and vibrant. They did all share the same white cinderblock utilitarian simplicity that contributed to a feeling of institutional efficiency.

The aesthetic and mood of health posts was reflected in the Municipal Secretary of Health's office with its one story building full of maze like hallways made additionally complex by a constant state of rotating construction. I circulated through several rooms of the office doing interviews. On the days where quiet offices were hard to come by or the heat was simply too much for the window AC units to handle, we crossed the street to the large shopping mall where the Commission on Integrative Health Practices (*Commisão das Practicas Integrativas* PIC)

sometimes had their meetings in the mall cafeteria. Additionally I met participants at local coffee shops (*paderias*), their private practice consult spaces, in their homes and on one occasion, on a boat.

4.2.6 Data Collection and Methods

In order to compare and contrast choices in the anthroposophic and SUS medical community in Brazil, and to design appropriate interviewing tools for semi-structured interviews, I first conducted two months of language training and preliminary research with founding AM clinic members in 2013.

Beginning in March 2015, I returned to Florianópolis for 12 months of fulltime research. I conducted in-depth semi-structured interviews with physicians and patients as well as participant observation in clinic and Sagres lectures, community events and workshops. Over eight months I participated in 70+ hours of anthroposophic medical training in the *Foundation Course* at Sagres offered through the Physicians Association of Anthroposophic Medicine in Brazil (ABMA). Participation in AM coursework offered a foundation for building an understanding of AM approaches to health from a providers' point of view. The training provided a window into the principles and procedures that shape the health practices and standards of emerging AM practitioners and a greater understanding of physicians' approach to patient care. Course materials and additional recommended reading were integral to forming comprehensive knowledge about AM practices and conceptions of personhood.

Interviewing was the main source of primary data for the project. Over the course of a year, I conducted 83 formal interviews with patients and physicians and numerous informal interviews with neighbors, community choir members, and regular participants/attendees at the

local community center. All but one of the formal interviews was audio recorded. Interview participants were divided into four samples: AM physicians, SUS physicians, AM patients and non-AM patients/strictly SUS patients.

I began the project with AM practitioners who were initially recruited at The Clinic. Clinic staff held a regular weekly meeting where I was invited to attend and explain the project. I followed up with the entire staff roster including anthroposophic psychologists, psychiatrists, gynecologists, biographic counselors and art therapists. The practitioners at the clinic also made additional referrals to other practitioners on the island as well as visiting lecturers (all AM physicians) for the *Foundations Course*. Interviews focused on practitioners' history in the healthcare profession, experiences working with SUS (pre and post PNPIC) and their approaches to patient care. Interviews also included whether physicians see patterns in patient seeking behavior. Over the research period, I interviewed 15 AM physicians (8 men and 7 women) and 7 additional practitioners who worked in AM art and music therapy, biographic counseling, and psychological and psychiatric work (5 women and 2 men).

For SUS physicians, I recruited physicians from several health posts across the island instead one health post or hospital. Health posts are both busy and under the auspices of the Mayor's office, requiring additional permissions in order to conduct research on site. In order to recruit physicians, I contacted the head of the Commission on Integrative Health Practices and was invited to present my project to the commission. With the help of the commission and the approval of the municipal secretary of health's office, I was able to contact all of the members of the commission for interviews. I was allowed to recruit directly from 7 health posts, which were given advance notice of the projects purpose and scope as well as my background. Several commission members also made recommendations for other colleagues who worked at their

health posts. Interviewing commission members had several advantages beyond their medical expertise in SUS. They were familiar with AM and the PNPIC and were able to describe how SUS has evolved to include other healthcare forms and how that process has progressed. Over the research period, I interviewed 16 SUS practitioners (one without an MD) (11 men and 5 women). During the university administrators' strike, I was also able to informally interview integrative health providers who worked in *biodança*, reiki, acupuncture, psychology and Spiritism. The same interview guide was used for AM interviews was used in SUS physician interviews for comparative purposes.

In order to examine how patients interfaced with multiple healthcare settings and understand their views of these settings, I conducted semi-structured interviews with AM and non-AM patients[17]. All but two AM patients were recruited on The Clinic or Sagres premises. The attending physicians offered to explain my project to patients at the end of their visit using a preapproved verbal consent guide. If patients were interested, I was seated in the waiting room to meet them and schedule an interview. If not, they simply passed through reception. This process insured that patients did not feel coerced and that no one in distress was asked to participate. Several patients were recruited from the *Foundations Course* as well.

The minimum sample of participants established on an ad hoc basis was 40, 20 AM patients, and 20 non-AM patients since I was not trying to control for other factors beyond gender. The actual number of participants exceeded this number. All participants were over the age of 18 representing a range of ages from late mid-twenties to mid-sixties. I sought equal participation by both men and women of variable ages since different age groups and genders typically have different health related concerns and conditions. The sample is slightly biased

[17] AM patients may also be SUS patients. Therefore, non-AM patients refer to individuals who primarily use SUS for their healthcare needs

toward individuals in their thirties to fifties since those in younger demographics were less likely to appear for routine care. Recruiting men in AM and non-AM was slightly more difficult since men were less likely to seek medical care unless they were in grave danger or agony. Providers and even patients in both SUS and AM fields explained this was a widespread and consistent trend. The proportion of men to women interviewed and age are representative of the patient population using The Clinic, however. I interviewed 30 AM patients (23 women and 7 men) over the course of the research period, recruiting 5 from that sample for illness narrative interviews.

To generate a sample of non-AM patients whom were similar to the AM sample, each AM patient participant was asked to recruit one or more non-family member who they saw as "like themselves" to participate in interviews ideally from their neighborhood. Non-AM patient participants were selected from that list. This was designed to enhance the likelihood that the sample of non-AM patient participants was as comparable as possible. While all of the patients agreed to match to themselves, several patients did not do so or matched themselves to individuals who were not interested in participating in the study. On one occasion, a participant matched herself to a man seeing him as most comparable. In the cases where patients did match themselves, through contact and neighbors, I attempted to match those individuals by age bracket, gender and whenever possible, neighborhood for approximate socio-economic status. I interviewed 22 non-AM patients who primarily used SUS (16 women and 6 men). A summary of the participants' regions can be found in Table 1. For the purposes of privacy, even though patients were generally matched by neighborhood since neighborhoods were consistent approximations of income, they are grouped below by district. The AM community is small so including neighborhoods would identify several of the participants. Anyone who lived in

Florianópolis but off the island, is identified as "mainland." Districts in the city center are identified as "Florianópolis."

Interviews with both samples of patients were used to document the practical and ideological motivations underlying patient choice (and patterns of health seeking behavior. Interviews with AM patients examined why patients chose AM, how they used these services and whether patients combined AM services with SUS services. Interviews with AM patients centered on patients' experiences within AM and SUS and how these experiences shaped how they used medical services. This included questions about their history with AM and the expectations and standards that they had for care. Interviews with non-AM (SUS) patients, using a nearly identical interview guide, focused on their experiences within the SUS system of care, what their ideal norms for care were and whether they used any other forms of "alternative" care. These interviews primarily focused on the healthcare experience and care seeking strategies of a non-AM patient in order compare and contrast AM and SUS patient experiences and choices.

Table 1 Summary of Patient Participants From AM and SUS by District

District	Number AM patients	Number of SUS patients
Cachoeira de Bom Jesus	0	0
Ingleses do Rio Vermelho	0	0
São João do Rio Vermelho	0	0
Ratones	2	1
Canasvieras	1	2
Santo Antônio de Lisboa	0	1
Barra da Lagoa	2	1
Lagoa da Conceição	7	5
Florianópolis	4	4
Campeche	5	4
Ribeirão da Ilha	1	0
Pantano do Sul	1	1
Mainland	7	3
SUM	30	22

Initially, I wanted to use Illness Narratives to explore the health beliefs of patients more thoroughly. Building on the work of Mattingly and others (Kleinman, 1988; Mattingly & Garro, 2000), extended illness narratives were going to be collected from a subset of five AM and five non-AM patients. Only 5 of the 30 AM patients referenced major illness and treatment with AM. Of these 5 only 3 agreed to illness narrative interviews due to their length and difficult subject matter. Matching these patients also proved to be impossible. While I had hoped these interviews would give additional data about how AM patients conceive of rights and responsibilities in healthcare, they added little additional information to previous semi-structured interviews.

4.2.7 Limitations

There were several limiting factors throughout this project. Brazil was in a state of unrest that climaxed with the impeachment of the President shortly after the completion of the project and national protests over Temer assuming the presidency. The city experienced repeated strikes that disrupted transportation, banks, healthcare posts, hospitals and university activities. This meant a four-month delay in approval of paperwork to interview SUS personnel. During this time, I spent the days with members of my neighborhood, community choir and worked with a group of traditional lace makers at the local community center. These interactions allowed me to conduct a number of informal interviews, as well as observe how people were using the system In addition to being slowed down by protests, El Niño contributed to two months of solid rain, which washed out the road to The Clinic on several occasions and wreaked havoc on the roads

making transit around the island significantly slower and arduous. Participants were less inclined to cross the island to meet for interviews or consults with longer transit times.

As mentioned earlier, matching proved to be somewhat challenging when patients did not match themselves particularly in the case of men, who were difficult to recruit in the first place. All practitioners reported that men were less likely to come for medical care than women and only when they absolutely had to. Men also reported this when asked about their own health seeking behavior. Women were more likely to be taking their children to appointments as well, making them more prevalent in The Clinic than their partners. This led to a slight imbalance between male and female participants and occasions where matches could not be found or had to be drawn from other neighborhoods. Physicians were also not matched. This was because the diversity of the backgrounds (many from outside Florianópolis), and multiple specialties and locations they worked in made creating a match relatively impossible allowing for *some* differentiation in responses to be potentially a result of where physicians were trained, their gender, specialty, age and length of time working in the area.

An unexpected limitation was the inability to observe physicians within consults. While I was a patient on several occasions when falling ill during the field season and was able to see AM physicians interact with patients outside of consults in medical settings in addition to speaking to patients and physicians extensively about the process, onsite observations were impossible for several reasons. While AM physicians believed this would be unduly intrusive given the extensive amount of personal information shared during a consult, SUS gatekeepers felt this would be problematic in terms of liability requiring additional permissions with were already tied up due to protests and the slow pace of ethics approvals committees.

Finally, while it was clear that AM patients were receiving a different form of medical care that conceptualized the human being than SUS, and that patients had a different view of the rights and responsibilities of the doctor and patient according to this vision, it was unclear how much AM shaped this alternate view of personhood, and how much of a non-conventional view had pushed patients to seek out AM in the first place.

4.2.8 Data Analysis

All but one interview was audio recorded. A resident l inguist transcribed all interviews verbatim in Brazilian Portuguese. All identifiers were removed prior to transcription and analysis. After data collection was complete, all transcripts, supplementary materials, documents and field notes were imported into MAXQDA for data management and analysis. This allowed for a comprehensive thematic analysis across data types as well as provided a systematic review of the data for the purposes of uncovering additional thematic categories and sub-categories for content analysis (Bernard, 2011; Bernard & Ryan 2010). A priori codes included *integration and syncretism, negotiating and defining personhood, membership, rights and responsibilities of patient and doctors, ailments, AM techniques and ideologies, expectations and experience of healthcare, and healthcare as a right of citizenship*. The constant comparative method (Bernard 2011; Bernard & Ryan, 2010) was used to inductively identify themes throughout the research period. Responses from SUS and AM groups were compared to identify contrasts between patient experiences, constructions of personhood and meanings of citizenship. The project adhered to the ethical codes of the American Anthropological Association, the University of Pittsburgh's Institutional Review Board, and a Brazilian CEP (IRB). The findings for this

research can be found in the summaries of each chapter sections as well as the concluding chapter.

5.0 CHAPTER 3: *O SISTEMA ÚNICO DE SAÚDE* AND THE PRODUCTION OF PERSONHOOD

The creation of a national healthcare program for all Brazilian citizens represented an important moment in Brazil's history – one that has continued to reverberate throughout the present shaped by new challenges and opportunities. One of these opportunities, was the initiative to expand service through the inclusion of *practicas integrativas e complementares* (PICs). Not surprisingly, since this research dealt directly with the Anthropsophic medicine, SUS physicians who were also interested in the PICs as practitioners of one or more forms of integrative medicine themselves were the most enthusiastic about participating in the research. Therefore, the majority of SUS physicians interviewed for this research were also practitioners or enthusiasts in integrative health practices, or had been referred by someone that was. The Commission of Integrative and Complementary Practices (*Commisão de Práticas Integrativas e Complementares)* at the Municipal Secretary of Health's office also referred physicians to participate. The participation of SUS physicians who were knowledgeable about the state of PICs in SUS and/or the PICs themselves provided important context for SUS's relationship with AM as well as the process of integrating PICS and SUS.

SUS participants ranged in age and specialties from long standing health post physicians who helped create SUS, to newer generations working to make treatments like acupuncture both standardized and widely available to SUS patients. With this variety in mind, SUS physicians

shared many of the same views on the challenges, successes and even future directions of the healthcare system but were less uniform in their responses when it came to discussing patients. Long standing physicians had personal experience with SUS in its fledgling stages through what it has become, which added additional layers to the perspective of SUS's evolution over the years both in terms of its victories and ongoing challenges. This was also helpful in understanding how the growing population on the island, and the thousands of summer visitors in particular, impacted the municipal health posts' ability to serve the residential population over time.

A prominent theme woven throughout all SUS physician narratives was the degree to which physicians found purpose and meaning in their work and how they intertwined explanations of their approaches to patients and evaluations of the system with narratives that highlighted the "public good." The physicians who stayed in SUS embraced the dynamic challenges of working in health posts and hospitals. The diversity of class, age, ethnicity and condition was a hallmark of the public physicians' daily care, and one that they often used as a benchmark of their own uniqueness compared to private biomedical physicians as well as anthroposophic physicians, whether or not this distinction was actually the case. One of these these physicians who had been working in public healthcare explained:

> It is good work, and intense work and work that is very dynamic. It is a job that is very uncertain. I deal with very simple situations; I deal with very complex situations. I work every day attending people of all ages and health conditions. I attend very acute things, chronic things, things of the body and things of the mind. We work on group activities, and will go all the way to the houses of our patients.

Dedication and patient care was nearly always framed by the context of public service – an important distinction SUS physicians often made between themselves and those who cycled through SUS transitioning to strictly private practices. Some of the physicians I interviewed disclosed they also had private practices as well. Having a private practice, while often

negatively associated with capitalism and consumerism, did not seem to detract from the aspects of public service SUS physicians attributed to their own work and to the work of their colleagues, however.

5.1 SUS FROM THE PERSPECTIVE OF SUS PHYSICIANS:

5.1.1 SUS as a national program and "local" reality:

Civil responsibility, citizenship and public service were reoccurring themes in SUS physician narratives and in their descriptions of their own experiences working in different health care contexts whether they were health posts, hospitals, emergency rooms, the polyclinic, outpatient care, inpatient care, PICs, surgery, or family medicine. Florianópolis stood out as having a solid structure of healthcare distribution and service as well as services that one could not find in surrounding areas particularly doctors who had worked or trained outside of Florianópolis. Patients who suffered major accidents or illness that impaired motor function, for example, commuted long distances for physical rehabilitation services that were not available in their own cities. SUS physicians highlighted the variety of access, services and quality throughout Brazil particularly when contextualizing public healthcare delivery, challenges and responsibilities.

The quality and success of SUS healthcare varies greatly geographically in Brazil as well as historically, which was a point AM and SUS physicians both referenced to contextualize their understandings and assertions about that system and its role in Brazilian society and politics (Buss and Gadelha 1996; Gragnolati, et al. 2013; Jairnilson Paim 2011). One physician, who had graduated from her medical training in Florianópolis in the early 1980s, described a radically

different state of affairs before democratic reform. While there had been various health posts, they were often understaffed and under resourced. Democratic reforms were motivated by and contributed to significant civil participation and activism, particularly in the health sector. Many of the physicians who began their careers in this era harkened to the intense idealism of the time that was now somewhat preserved within the Commission on PICS. The idealism that motivated Sanitary Reform in the late 1980s was reflected in the commission's efforts and hopes for the system to amplify care and access through the PICs themselves and their practitioners (Gragnolati, et al. 2013). One physician who was recommended to me for an interview by a commission member, explained the difficulty in realizing many of the goals born out of the idealism of Sanity Reform. He worked in a low-income neighborhood and while he practiced acupuncture, he spent a great deal of his practice taking care of acute problems, not necessarily using the acupuncture he had learned. He still believed in this idealism, however, stating:

> There is this possibility that a group of idealists, from the epoch of Sanitary reform, also exists in the effort to introduce alternative practices in the healthcare network. They do more than just the consult, fulfilling their role and checking the box. We want to do more. We are the majority in Florianópolis I think within the system. The people that are here are here because they want to be here. They are in public health because they want to be in public health. It is more than an obligation. They might not do alternative medicine, but they do a thousand other things; they do theater or make a community dance group, or whatever. The people are very intuitive and creative. There is a mountain of things happening on the island because these people have an interest to actually do something for the community. That being said, I have not been able to do much on the "alternative" side because of the constant rush.

Many of SUS physicians involved in promoting the PICs were more idealistic or optimistic about the system than their AM counterparts, especially if they had worked in other areas of Brazil. The sentiment referenced above of "actually doing something" was deployed in multiple directions almost as a counterweight to the dragging pace of bureaucracy. Likeminded individuals within the system advocated for all sorts of offerings whether that was new trainings for physicians, to study groups and workshops. They recognized, however, that not all SUS physicians shared this idealism or dedication to public service and that some physicians practiced

in the public system through obligation rather than by choice. Overall, however, Florianópolis' cited success in offering quality healthcare was largely attributed to a dedicated majority of physicians who embraced the challenges and rewards of public service.

When discussing the current structure of SUS and its role in public service, many physicians referenced the history of the system and its political beginnings. Physicians described how SUS was used not only as a means of improving health, but first and foremost as a political strategy or benchmark of returning to a democracy, strategy noted in other countries (Jairnilson Paim 2011). Others felt that SUS's objectives would never have been realized or even so ambitiously stated had it been unrelated to Brazil's political upheaval and transformation in the late 1980s. These narratives were inextricably tied to the contemporary upheavals in the country and national protests over austerity measures, impeachment proceedings and corruption scandals.

The idealism that many in the international health care community had felt about Brazil through its struggle to address the unequal distribution of power and resources and its momentum to achieving MDGs as well as economic milestones had been somewhat deflated by national unrest and frustration (Fleury 2011; Jairnilson Paim 2011; Kleinert and Horton 2011). Health posts and healthcare workers staged numerous strikes and walkouts during the field season although these were remarkably absent in SUS physicians' description of the system as it was presently. Even while interviewing physicians who happened to be available because they were on strike that day, very little mention was made of the current political issues as opposed to the ones that ignited the reform in the first place. While the strikes and current political system remained less highlighted, SUS physicians were forthcoming about the day-to-day challenges of the public system. As one physician explained: "*SUS's objectives were good objectives, marvelous objectives; there is no better ideology. The problem is transforming it into practice*."

Brazil's flag is inscribed with the phrase "order and progress" and these two ideals were as much a part of goals of creating SUS as it was in expanding SUS through the PICs. Decentralization of healthcare resources was designed to increase access for all in a system that was historically both class dependent and determined by participation in the formal economy. Appeals to rationality were central in narratives justifying policy and service delivery (Gragnolati, et al. 2013; Jairnilson Paim 2011). The PICs themselves were referred to as medical rationalities where only practices with a certain degree of "systematization" in diagnostics and treatments were "allowed" to be included (Brazil 2008; Luz and Afonso 2014). In a country with great divides between the "haves" and the "have nots," public healthcare was both raised as an example of the quest for equity by doctors and example of inequity by some patients (Caldwell 2017). For physicians, SUS was supposed to be based on and executed according to these principles of rationality on the level of what kinds of medical care is offered as well as the bureaucratic aspects of how medical care is offered. One female SUS physician I met in my neighborhood and had just retired, greatly believed in SUS' principles although she stressed the continued need for the system to be vigilant in its organizational principles. She explained:

> The rights of citizenship are something that I think the whole country would like to see lessen the difference between Brazilians. So it is a civilizing principle. Another principle is the principle of coordination across different levels of care and organization; in this sense it is a structure of organization of the network that is also very rational because to guarantee equity, you have to be rational in your care or there will not be enough funds for all of the entry points of care.

The principles the physician references here allude to the official principles of SUS: universality, equity and integrality, which SUS physicians generally agreed on although occasionally took some poetic license in defining (Gragnolati, et al. 2013). Cost effectiveness, included here by this physician for example is likely more of a result of the permeation of market forces into medicine than a result of Sanitary reform especially since SUS physicians do not take an oath to heal cost effectively so much as work to heal.

5.1.2 SUS: the mission and the profession

The principles explicitly included in the constitution were the foundation of SUS as a medicine for "the people" that was also a means of solidifying a certain sense of public order and rationality. Despite a cited commitment to providing and furthering a rational system of equitable healthcare for all, most of the physicians started in medicine for other reasons. Unlike most of the AM physicians interviewed, many SUS physicians pursued medicine because they came from families of doctors, were encouraged to by their families or chose it because it was a dependable career path. Many physicians described having interests in science and research beforehand, while others considered pursing careers in journalism, literature and philosophy. A select few expressed a longstanding affinity for helping people – an affinity that most doctors also experienced later on in their careers as public healthcare professionals regardless of why they began their careers. SUS physicians regularly cited being drawn to and kept in the public system to address an unmet need that was both practical in nature – the line of patients waiting for help – as well as existential – the need to live up to the ideals of democratic reform and the public health care system and continually evolve it. This physician, for example, saw a need for a paradigm shift in medicine and he was attracted to the field in part to help create that shift:

> I was looking for a profession. I took classes in mechanical engineering but was not satisfied. And then I came into contact with literature that spoke about a paradigm shift – Thomas Kuhn and others – and it described in health a course for change … the necessity and the course of change in the paradigm in health because biomedicine is fragmented, materialist too and positivist and various other characteristics. It resurrected a great deal of the questions of ethics even altruism of the health professional in order to work to ease suffering. In the end, I felt interested in accessing this knowledge, to study this field with other people already using this different logic and to help to create and establish this new field.

Both long-term physicians and younger generations referenced the promises of a new democracy in healthcare reform and their dedication to making the promise of equity a reality. Several doctors, who had been working in the area for over 20 years, expressed this regularly

since their trajectories in medicine were rooted in the era of healthcare reform. Thus, *saude pública* was inextricably tied to history and the legacy of the past as well as a continued hope and dedication to a better future for all Brazilian citizens. One doctor spoke of his early medical work along side the MST "the landless workers movement," which sparked his interest in family and community health and politics. These early experiences often clashed with his perceptions that many in medicine chose the career for economic reasons rather than being called to it to contribute to the collective good and the promises of democratic and sanitary reform. This often manifested as issues with current medical trainings, motivations and attitudes. He explained:

> I started in medicine but I thought it was horrible. It is enough to say that at first I wanted to be a doctor but did not like it anymore because there were some guys who thought they were superior. I started to study medicine and oceanography too participating in conferences. But in my second year of university, I came into contact with social medicine with a friend who worked with a group of Catholic nuns – the Sisters of Divine Providence. These nuns owned the 20 largest hospitals in the state but they also worked in the mountains, the favelas and such. And there I started learning to evaluate and really see in order to diagnose. And I said, "this is a different kind of medicine" and I started to fall in love with it and then it was decided that I wanted to be a doctor, that even if I was born a thousand times, a thousand times I would want to be a doctor. And that is how it was.

Doctors also expressed the social aspect of "*saúde colectiva*" or "*saúde pública"* as its own form of medicine and approach. This was particularly strong when doctors explained their path in family medicine compared to other colleagues who had pursued specialties and often worked outside of the public healthcare system or within it on a contractual basis. Specializations were considered more lucrative and prestigious but also further from serving the collective good associated with family medical practice. Specialists were both venerated and resented since they were a rare resource that patients often had to wait long amounts of time to access. Waiting times were a chief complaint for patients, particularly when trying to see specialists, a pattern noted by scholars working in other areas of Brazil (Gouveia, et al. 2005). In one case, a patient had died of cancer a full year and a half before they called her daughter to let her know the appointment for

diagnostics to test for the cancer was available. While in the field, a new law was passed mandating a shortened maximum waiting period for patients who had acute health concerns, however.

5.1.3 *Saúde Collectiva* and the public good

Public health and family medicine seemed to both reflect the promises of health reform and embody those ideals for SUS physicians to the greatest degree. Family medicine remained "closer" to the people, responsive to the need, and avoided the labels of bourgeois and self-serving programs often associated with mixed private public practices. Some physicians worried that the newer generations of doctors and medical students were drawn to the profession for its prestige and its earning potential seeking work in the most lucrative and well-developed cities and neighborhoods while others had hope that the ideals that ignited Sanitary reform were being reborn in the next generation of physicians.

While many physicians flocked to Florianopolis to practice in a developed and well-structured area and health system, keeping physicians consistently at a specific health post remained difficult. Some maintained private practices or worked at several health posts while a select few worked at one or two health posts for decades at time. Circulating physicians fragmented the system by making continuity of care more difficult. By contrast, the veteran physicians were both trusted and respected seeing patients through childhood, births and deaths of all their family members in the area, and sometimes long after they had moved away. The doctors remained in a health post for years at a time had done so quite consciously as part of their public service and contribution to the public good. When explaining the meaning of *saúde collective,* the physician quoted about who worked with the nuns:

> In a way, it was important for me to be inside *saude coletiva*. Of course the economic question was a large influence on my choice but my purpose was never to earn money in the sense of wanting to become rich and make a lot of money; but rather to sustain myself, to live in a dignified way with a profession. Inside *saude colectiva* and Brazilian public health, which has only become reinforced since I graduated, the people with the better capacities, and sometimes those that have already qualified to work in a specific health sector, stop working there. They migrate to other sectors because there is not a whole lot of control over them. So for me, to remain in one area and contribute … today that area has already changed a great deal. For me to be able to give this social return is important. I come from a large family that always relied on public school, public health and other things and so to see these health sectors function is something important to me.

It was clear that patients also valued having the same physician stay at the health post for extended periods of time. It built trust and a sense of reliability and coherence that both SUS and AM patients expressed as important. These physicians were the ones patients took it upon themselves to refer me to for interviews. Even patients who had long since moved away from an area would suggest I go speak with one doctor or another who had treated them since childhood and treated their own children as well. Unfortunately, these doctors seemed to be the exception rather than the rule in terms of their ability and desire to stay at one health post over the years. This chapter will further explore some of the issues of keeping doctors in less desirable areas and the use of Cuban doctors to fill the gaps in the section on the challenges facing SUS.

5.2 THE SUS APPROACH TO CARE

5.2.1 The organization and institutional aspects of SUS healthcare:

SUS physicians were part of healthcare teams that attached to a particular health post. Each team was supposed to be responsible for about 3, 500 people living within the health post's municipal borders. One health post, for example, had 5 doctors and 5 health teams for 20,000 people living

in the area. Not all of these 20,000 people, however, were regular users of SUS. Due to decentralization, the number of people each health team was responsible for varied especially between areas of high and low population density (Assis, et al. 2003; Gouveia, et al. 2005; Jairnilson Paim 2011).

The basic routine of the health post revolved around the health team and an approach they called *acolhimento*. Most physicians worked most weekdays for a full day or either mornings or afternoons at the health post. Some physicians for example divided their days between private practices and the SUS health post working a mixture of mornings, afternoons or both during the week. During their time at the health post, consultations were a mixture of scheduled appointments and spontaneous demand. Spontaneous demand was generally on a first come first serve basis limited from six to eight patients per period. Thus, half the morning (approximately two hours) and half the afternoon periods were dedicated to spontaneous demand. Patients took a number and passed through triage with a nurse who was the first point of contact with the patient. The nurse decided whether the patient needs to be seen more urgently by a physician as well as whether their health condition could be addressed with the nurse rather than the physician. Once their number was called or the urgency of the health condition moved them to the front of the line, patients were then passed to consult with a physician.

Spontaneous demand was the period of time and demographic of patients that physicians usually linked to the diversity of their practice in our interviews. They had to be prepared to address a variety of health concerns across all demographics on short notice. The second half of the agenda – scheduled patients – were generally patients who were there for follow-ups, exam results, scheduled regular visits for individuals undergoing treatment, hypertensive or diabetic individuals who have to return to for monitoring and renewing prescriptions, pregnant women,

and patients who were using controlled medications for illness such as depression. Scheduled patients usually made their appointments far in advance, marking a visit every two months for example.

For non-ambulatory patients, health post teams made house calls, which were also scheduled on a particular day and time period. Typically a nurse or nurse technician accompanied a physician when they visited patients who cannot make it to the health post. The number of these house calls varied depending on need. One physician had 14 non-ambulatory patients so she visited three or four every Thursday during the afternoon – a period set aside specifically for house calls.

In order to coordinate care across the healthcare team, one team's physician, nurse, nurse technician and community health agent often meet for two hours a week to discuss patients. They also have a full team meeting once a month with the physician, core personnel from the family heath support team, a social worker, psychologist, psychiatrist, and sometimes the nutritionist (if the post has one). There are additional meetings especially in the beginning of the year for the organizational and planning work of the health post. Health posts have their own ways of doing things, however, so there was some variation from post to post on how they coordinated and delivered care.

5.2.2 SUS physician's approach to care and defining "good" practice:

SUS is designed to make sure each neighborhood or municipality is able to handle most of the health needs of their respective population. For a number of physicians, being a "jack of all trades" was a hallmark of its approach to patient care. They prided themselves on being able to handle the most minor, and to a degree, major health issues with evidenced based interventions.

Being able to do so in a quick and effective way was an earmark of professional ability and responsibility. Sometimes this included some experience or use with PICs while for other professionals, excellent practice was purely biomedical technique. In the physicians' statements below, while they tackle professionalism from different angles, they both highlight the idea of the multi-professional or multitasking although one connects this to PICs while the other does not:

> I believe very much in the physician that has a good education, who has a good clinical technique and is an excellent clinician. You need a critical vision of the evidence, of communication tools and to be able to deal with various situations that arise. It's not enough to know how to ask for or read an exam; you have to know how to deliver the news. You have to know the tools of primary care like coordination of care, how to work in a team and have the character of a multi-professional.

> Today I am trying to be a catalyst for this idea of the ideal doctor. We have to promote the vision of this ideal doctor and catalyze this kind of medicine, a more human medicine that aligns the excellence of technical knowledge with some … you have tools like antidepressants but you also know how to handle floral therapy to try with the patient, to know how to do acupuncture for this or that, to do auricular therapy. Anyway, being an ideal doctor is more or less this, this professional that is a multi-tasker – that is a family medical doctor.

When it came to defining what an SUS approach to patient care entailed, many physicians described, "patient centered care" and "holistic" approaches to health with numerous variations on what that entailed. While physicians often referenced the need to go beyond being a technician or diagnostician and attend to patients themselves, they often inadvertently contrasted their approach with the strictly biomedical approach to care that is an intrinsic part of SUS healthcare delivery. Terms like "holistic" and "patient-centered" were used regularly but the clarity of what these terms actually meant in practice was debatable. Technical practice and interpersonal practice while both valued were often placed in a hierarchical relationship to one another. As one physician put it:

> I argued a lot in undergraduate medical training, for integral training, breaking the paradigm of medical-centered and strict biomedicine, for a more holistic paradigm, a person centered paradigm that included the psychosocial factors. My clinical practice, I believe, reflects some of these ideologies. I was always concerned [about providing] integral care, with listening to people to understand their social context and at the same time, I was always worried about being a good clinician, to give a good biomedical answer to

> legitimize it. I couldn't be a guy worried about the social factors for example, without legitimizing my clinical practice otherwise I would undo the work.

Here the physician casts integrative care as a kind of rebellion and something he thinks is important yet contrasts with good clinical practice. "Good" clinical practice meant providing a "good" biomedical answer. It did not, however, seem to include listening to people to understand their social context, for example. There is a certain subtle acknowledgement that biomedical care and the materialism and technology that go along with it are both not enough yet are also the standard of practice. It is what one needs to be a legitimate doctor but not necessarily what makes one the ideal doctor.

The definitional clarity of patient-centered care also merits highlighting as it becomes something that is interwoven into reports and ideologies about medical practice that in some ways gives the illusion of difference between a present and historic approach that in many cases does not exist, and that patients were not seeing either. Even at the highest levels, the term "patient centered care" peppered the narratives of physicians and health care managers to such a degree that I began to ask participants to define what this meant to them and how they saw it operationalized in practice. This provided an important backdrop for how physicians interpret and produce care and how their visions of care delivery can be interpreted and experienced quite differently by their patients. Several of these definitions are included below for contrast:

> 1) With a whole set of techniques, which have a lot of inspiration from person-centered medicine, that is also a theoretical current in medicine, we have to take care to listen to people, to use open ended questions, to try to have people translate their fears and their pains. [We need] to give an answer to her that addresses those fears and pains – an adequate diagnosis - that addresses that person's demand of you; not that you simply make a connection between symptom X, Y, Z and sickness W. Not just to make a biological connection but try to respond and try to act accordingly.

> 2) My approach in this sense is being able to respect the point of view, the understanding, the knowledge of the person and her expectation of being there. In my profession, the person seeks us out, right? So you have an expectation when you are seeking something. And this approach allows for, most of the time, in the best possible way, the person to express what they bring with them. And that we also have the time, useful time, to guide them to the accessible possibilities. It's also so that the person leaves in the best way,

understanding what happened there. So this approach needs to be centered on the person, on the specificity of each person.

3) It's like this: the physician can't be completely manipulated by matters related to the pharmaceutical industry or the benefits he might have. He can't indicate certain treatments determined by anything for his own benefit due to the [pharmaceutical] industry's strong influence. Like this, he can't harm my care with governmental guidelines that earn money through certain diagnoses, products or certain attitudes. So it's a professional who combines great clinical excellence with an empathic, human vision and that puts me as the center of care.

4) It means a type of … that I am advocating; I am a type of lawyer/counselor for the patient. I have the medical knowledge that I acquired over those, I don't know, six years, plus two years of residency, plus the year I did acupuncture, for example. This professional [the doctor], he advocates; he has the knowledge and if the patient is debating, the doctor is open to seeing my [the patient's] peculiarities. For example, if I have a specific religion, if I have a specific sexual orientation, or if I have a certain vision of the world; he [the physician] knows how to respect this and can develop an empathetic, caring and personalized relationship. My training is based on the person-centered clinical method. My training advocated cultural competence as an important element of clinical work. I work from translation, to translate the technical field in order to master the problem, the complaint, the understanding of the person, how to translate the possibilities and alternatives to deal with the situation in the patient's own language.

5) I try to use an integral look, a natural look, a look free of prejudice. One can call it a holistic approach. I try to use what we call "person centered medicine", the attention to health centered in the person. So that's what that person brings me that day. Is it an acute thing? "Oh, I want to resolve this pain here, which began yesterday," or, "here's my life story and I'm stressed; I'm depressed from the day I was born until today." So, understanding this physical dimension, a psychological dimension, a spiritual dimension, an energetic dimension, right? Looking to address all those dimensions that we can have, right? Which, I think I'm a little sensitive to this, to try to perceive this according to what the person offers, and then try to connect, it right? What is that? What does the person bring? What dimension of the health or illness is it bringing about? What is he thinking about healing and seeking to see? Then you can help her more right? So I think it's a broader approach anyway, an approach not so focused on biomedicine, only on technology, which us tough, but it's a multidimensional look anyway.

The five definitions here cover a great deal of ground in what they want to accomplish although less so in describing how they actually accomplish them. The first response stresses listening. The second response focuses more on the health literacy and expectations of the patient in order to guide them. The third is mostly concerned about not being coopted by external pressures like pharmaceuticals and the fourth is rooted in a cultural competency perspective. The fifth brings together a more holistic view of the patient that one might find expressed by AM physicians. The physician who provided the fifth quote was trained in PICs outside of SUS. He also contrasts a person-centered approach with biomedicine. While AM physicians might make similar critiques of biomedicine and a technological approach to medical care, biomedicine is seen as a step

towards an amplified medicine that when combined with a more complete version, is important to comprehensive medical care.

From several of these narratives, it becomes clear that patient/person- centered care is plagued by some of the pitfalls that cultural competence training has struggled to overcome (Baker and Beagan 2014; Kleinman and Benson 2006). Patient centered care as a concept has also been loosely applied internationally to such a degree that its definitional clarity is muddy at best, which further fosters its liberal application as a buzzword rather than an operationalized concept (Miles and Asbridge 2016). The idea that asking about a concern makes the visit patient centered rather than doctor centered, for example, or knowing a few of the patient's demographic factors does not guarantee care that is culturally competent or appropriate.When asked whether a patient or person centered approach was the general *modus operandi* within SUS, this physician explained it was the exception:

> No, I think that here inside the unit and within the health network in Florianópolis, we have similar visions from medical professionals to other medical staff. I think I see … I encounter *reflexos* like this in many colleagues that think, that have a similar vision. The structure of the [health] secretariat itself already encourages us to search for this: this amplified gaze at health. But without a doubt, I think that it is a different group; a different kind of common sense. From the medical point of view that most people have, ours is a non-traditionalist view, an unconventional one.

The physician references the growing group of professionals who are now being encouraged to "amplify" their gaze. He references this as a wider look at health not necessarily at the patients themselves, however. This amplification is also cast as non-traditional and non-conventional – a notable parallel when one considers that the medical forms included in the PNPIC are simultaneously considered "new age" or "unconventional" as well as "traditional," although the latter is usually in reference to Brazilian indigenous practices. Even forms like acupuncture, which are often referred to on an international stage as "traditional medicine" acquires an alien quality once transplanted in Brazil that it does not lose whether it was integrated by the PNPIC

or not.

5.2.3 PICs and cultural diversity in Brazil

The PICs played an important role in this nexus of patient or person centered care. PICs utility in highlighting and meeting the diversity of needs and beliefs of patients did resonate with physicians treating diverse patient populations especially given the immense influx of people brought during Portuguese colonization and large waves of immigration long after Brazilian independence including Ukrainian, German, Italian, Japanese and Lebanese immigrants (Lesser 2013). In Florianópolis, the last names – and to a lesser degree first names – of the long standing residents of the area also often reflected the Azorean, German, Italian and to a smaller degree Ukrainian heritage of the area, which did add some diversity to the home remedies, food and sometimes social practices of patients. Some doctors acknowledged that PICs or other forms of spiritual and cultural practices were important to meeting their patient's needs. Alleviating suffering also meant being able to connect with a patient and their context. This was a challenge in a nation as diverse as Brazil. One physician explained this within his approach to care stating:

> Brazil has a great deal of pluralism. Because healing passes through culture, if you do not heal the person within their own culture, they are not going to become well. They are going to say that you do not understand what they are saying. You will not be able to get close to that patient. It will be as if you are speaking another language. That is why it is important to stay in a place – to feel the culture. So it is like that; that is the way you are going to practice medicine.

This physician had spent decades at the same health post, which was unusual within SUS. Physicians often worked at multiple posts or rotated posts or positions after several years. I encountered very few SUS physicians who expressed being so connected to an area and the patients they served within their municipality. It gave him a sense of context for patients, some

he had been seeing since they were children. It also seemed to provide a degree of insight into patient context that other SUS physicians did not reference. One such example he provided was a case where one of his patients, who had fallen ill and was expressing some psychotic behaviors, had been sent to a mental institution for evaluation and treatment. The patient's condition did not seem to improve with treatment, however. When he asked the family what they thought had gone wrong, they explained that because the patient had eaten taboo food, he had become possessed. So the physician brought in a friend of his who practiced *macumba* and had him do an exorcism. The man recovered and reintegrated with his family without further problems. While this physician did not necessarily believe his patient had been possessed, he recognized the importance that this belief played in the patient's ability to reintegrate with his community and family as well as its role in reducing mental health stigma. It was a means to reconnect his patient who felt depressed and isolated by his symptoms and subsequent institutionalization. The physician used this case to underscore his point that patients needed to feel treated according to their own cultural contexts.

5.2.4 The time and technology gap between the "old school" and "new school" approaches to care.

Physicians, who had been working the public health system, especially during the era of healthcare reform, were exposed to a diverse set of treatment contexts, geographic regions and medical training. These physicians were the ones most likely to exhibit the "barefoot doctors" type of model with echoes of Liberation Theology, or Brotherton's "new man"– a vision of a doctor of the people that was charming and deceptively simple in its message (Brotherton 2012). These physicians were more likely to reference the necessity of skills like listening, living with

the communities they served and investing in the area. A physician, who also taught medical students, captured this in his description of teaching new medical students how to approach patients. He was concerned with the motivations of medical students in their choices to become doctors and wanted them to focus less on technique and more on skills like listening:

> I am basically looking and seeing. The person sits and I look to follow what he feels, waiting like this. It's not so much what the words mean but what is happening with him – more or less like this. And sometimes crazy things happen because I am not in a rush – I say to my students: "do not get carried away by the pressure of the dam." Because you might have 40 people arriving and I am going to want to attend quickly. No. I am going to attend at my pace, in my time. Then incredible things happen. I think that when a person complains because the consults take time, they become content when they are attended to. And so basically I listen because the majority of people don't have a place where they can talk and have qualified listening. The conversations are usually banal: "who won the game yesterday? Did you see the plane crash? Did you see they assaulted I don't know who?" Some things have nothing to do with anything. And sometimes they need to talk about what is causing them trouble.

The physician continued to discuss the value of time in forming a patient bond or "*learning enough to be able to talk*." He was interested in the narratives of his patients and in taking the time to hear them in part due to their content and in part to form a bond with them and to allow them to share what ailed them. The flexibility he had to take longer appointment times was rare and something most physicians expressed not being able to do even if they wanted to engage in "patient-centered care."

Along with referencing the need to engage with the culture of their patients and the role of time and face to face interaction this required, some SUS physicians referenced their approach to patient care as one that included the "lifeworld" of their patients like the narrative above. It was in the lifeworld that physicians gained clues to their environmental and social causes of disease. When queried whether their approach was something endemic to SUS, most credited this approach either with decades working in community health, training in PICs or alongside lay community health workers, midwives or simply by having avoided medical specialization in

favor of community and family medicine. While they often defended SUS with impassioned descriptions of patient centered care, many admitted they felt that they were the exception rather that the rule in their approach in how they were trained and how they practiced:

> No I think that very few do this because everything is being based on technology. And this medical industry and equipment, it determines the [medical] curriculum. So these people graduate very insecure about coming up with a diagnosis; they don't feel capable of saying "I think it's this." So they need to be grounded in technology, and technology unfortunately drives people away – the further away the sicker they become.

Another physician echoed this concern:

> We have been at this for two hundred years, right? We've run an arms race in medicine in search of technology, technology, technology. And we have stopped looking at the human side. We went to the mechanical side of the body. It's more exams, more machines, more this, more that and stopped looking at the patient. For man, right? For the social being. Be cultural! You move the individual from the Brazilian backlands and send them to São Paulo. There the guy lives on the outskirts, goes two hours by bus a day, does not have the food he is accustomed to eating. In fact, even eating right, he cannot eat. And you want him to be happy and healthy? No he will be a sick person, but it will not be with medicine that you will solve his problem.

A recurring frustration especially among physicians with decades of experience within the health system was the attitudes of some of the younger doctors who were more enamored with the technical aspects of care. Some attributed these attitudes to training while others attributed it to a lack of time with patients. Several SUS physicians expressed concern over the dependence on technology and its effects on doctor patient communication. Others, like the physician here, explained that communicating was not always possible or desirable in the practice setting emphasizing the values of exams and physical examination rather than conversation. The physician on quoted on page 97 repeatedly emphasized this concern stating:

> Today medicine is not concerned with communication. I am going to ask for an exam/labs for you. But an exam has nothing to look at. An exam is a way to delay a conversation. If I am a bit pressed for time, I ask for an exam. With time, I can examine you, your skin for example, but I need to touch you. But I can't hang around speaking with you. I need to look at you in order to know what you are coming with.

There seems to be a schism between what information needs to be obtained in order to treat a patient and where this information should come from. AM physicians were extremely consistent in how they described their approach to patient care and what kind of indicators they looked for while interviewing patients, whether that was their posture, tone of voice, medical history, pallor or symptomology. SUS physicians, however, often expressed a disjuncture between what they wanted to do and what they could do as well as what information patients could provide. Many SUS physicians expressed the need for understanding their patients' concerns and cultures while simultaneously asserting a physical exam rather than a patient's narrative, especially given time constraints, was the key to meeting the patient's needs. The physician above expresses this quite succinctly in how they manage patient input from the physical form rather than the narrative and how exams are a way to bypass the narrative.

5.2.5 The family doctor and the specialist

While physicians prided themselves on being able to address most of their patient's health issues within the health post through interdisciplinary healthcare teams, some concerns have to be outsourced to specialists. General practitioners seemed to have a love-hate relationship with these specialists who on the one hand provided needed expertise and on the other, often did not fit into the narratives of public service especially if they had private practices. These specialists, while incorporated, represented an almost fringe like status to family physicians – all at once accessible yet also somewhat removed as a necessary resource but one the physician did not want to have to rely on. When asked how she interfaced with specialists, one SUS physician explained how specialists are connected with patients:

> Generally, 10% of cases are situations that we refer to other professionals that are in the system. We have basic teams that are family health teams that have a doctor, a nurse, one or two nurse technicians, a team for oral health and the health agents. There are things, 70% or 80% of the things we can handle here. Other situations, situations of mental health, situations of joint pain and such, we ask for an auxiliary or assistant from NASF. *The Núcleo de Apoio à Saúde da Família*, was formed inside the evolution of SUS. We saw that these basic teams were good but were not able to handle everything. So we created, the nucleus – they are 14 professions that can be contracted as auxiliaries or assistants. Pediatrician, psychiatrist, physical educator, physical therapist, nutritionist, occupational therapist, social worker … there are 14 professions that can - it depends on each region and municipality – there is a composition that can assist with these other questions. Other than that, it is a matter of medium or high complexity. So if I have a doubt about a cardiac issue that I am unable to resolve here, we use virtual discussions; so I can send an email directly to a cardiologist colleague who helps me. Sometimes, we maintain the care of the person. We call this coordination of care. I continue to accompany the person, and I ask for an assistant or I refer them. The ideal is that person comes back, right? So I continue to accompany this person.

Despite the discussion of holism and teamwork, family health practitioners referenced themselves and their work within a sphere that while linked to specialty care, was somehow closer to the people and closer to the mission of SUS and its roots in democratic reform. The cardiologist was someone at the end of an email chain rather than a warm body on the front lines of the health post. Patient narratives often reflected this same removal from specialists – a mystical entity that was difficult to access in a timely way.

5.2.6 SUS healthcare's struggle with medicalization

Many of the SUS physicians, like the one quoted above, expressed the double edged sword of trying to get patients to return to the health post, to follow the healthcare protocol and take their medication while at the same time trying to dissuade patients who wanted certain exams or medications they did not need. SUS physicians were regularly frustrated by patients who did not feel attended to unless they had been medicated or subjected to a series of medically unnecessary exams. SUS physicians had to argue with patients to take medication and not to take medication, to see specialists for exams and to withhold referrals for other exams – a narrative that AM physicians only referred to when they discussed patients who self-selected out of AM care.

While SUS physicians eschewed this waste of public resources, they often found themselves unwittingly participating in the medicalization of life. The physician who I met and was retiring often complained about medicalization but she explained it was not was not a simple fix:

> We end up saying, this is a checkup; it's to listen to your lifestyle, to see how you live, to examine you, to weigh you, to measure you. I have this whole conversation, but at the end the person says "but you are going to ask for exams right?" And so I have to ask for exams because people are very dependent on this. The medical culture, the culture of the biomedical model, the biomedical market, of which the U.S. is a great precursor to this, the ones responsible – it is the American model there that says this. It is not that the biomedical model is not useful and innovative and that the technology is not useful, but the way that it [medicine] has been subordinated into a model that is to generate profit and accumulation … what is important is not to make people healthy, it is to ensure they continue each time more sick. Yes, because if you begin to do exercise your quality of life will improve and you'll stop coming [to the doctor].

On the one hand, this physician does not want to prescribe medication or exams but on the other, feels she has to in order to satisfy the patients' desires and expectations for care. These expectations, however, are attributed to American capitalism – something separate from the goals and roles of SUS and Brazilian democratic reform and from her practice despite her participation in medical consumerism. SUS by nature has always deployed a biomedical model, yet the technology and values associated with certain aspects of biomedicine are teased out and cast as alien to SUS. While simultaneously decrying the cooption of medicine by market forces, she orders the exams and does not encourage her patient to change lifestyle or pursue activities that would make them "less dependent" on the medical system. This dependency, while identified as a result of the American medical model, enables the disciplining and ordering of Brazilian bodies – an addiction to the system agents of the health system provide (Foucault 1963; Foucault 2010). Physicians have an ambiguous relationship with the medicalization of patients and with trying to encourage "self care" and making healthy choices in order to exit the system through responsible citizenship while also participating in the medicalization and validation certain forms of medicine over others that encourage continued participation in the system. One

physician framed this struggle as a negotiation over medical expertise as well:

> Often people arrive saying they went on the internet or that they went to a doctor who asked for a pap smear every six months, or asked for a rectal exam and PSA treatment for a man without indication. Many prescriptions, treatments, exams are according to a logic that patients want to have access to and frequently many of these practices have no medical basis or medical evidence. My approach is to stimulate this question of self-care. We live in a very infantilized society, at least in Brazil – I believe it has to be like this in other places that are consumerist. My role as a doctor is to discuss this self-care because fundamentally what I see is that most patients need to change their lifestyle. It is within this that I try to search to try and arrive inside what makes that person sick whether they think that is what is making her sick, or is behind it. Normally, it is lifestyle.

Another physician contrasted the danger of medicalization with the relative utility of it:

> Everyone wants medication. And I say, it can be better. For example, one time when I was working at the health post, I had to treat depression – it was a problem of public transportation in Florianópolis. I had to treat it with an antidepressant because the young women left work at midnight and had to wait at the bus stop dying of fear, stressed to a level of anxiety … the stress … but she could not leave the job because she needed the work. So what do I do? I give the *remedinho* to the person to calm them so they can remain less frightened and less anxious and can go to work.

The physician identifies the source of her anxiety and depression as caused by public transportation and the long wait for her bus to come late at night. He does not consider that her symptoms are a function of a chemical imbalance or some other physiological issue. The cause is public transportation and since he cannot fix that and she cannot change her job, he prescribes an antidepressant. Medication is the expedient solution and while he complains everyone wants medication, he also sees it as the better choice to alleviate suffering under the circumstances:

> And so, sometimes, for people it's faster to take medication. What are you going to say to the person that works 70 hours a week "no, you need to do exercise"? No, it is not easy, because these integrative and complementary practices emerge and also end being appropriated, appropriated by a middle class because the traditional Brazilian practices of origin, the origin of fitotherapy etc. these are being appropriated by laboratories who began to sell these remedies. Nowadays the herbal remedy … an herbal remedy today costs more than normal benzodiazepine.

In the two patients quotes above, one can see several conflicting narratives around the dangers of the cooption of non-biomedical modalities, yet the admitted utility for physicians to prescribe medication rather than lifestyle changes especially when patients expected to be

medicated. It also raises the question whether AM patients are more or less satisfied because they have to invest in AM services. Additionally, AM patients may be more economically able to achieve lifestyle changes than their SUS counterparts although a significant number of AM patients who participated were lower middle class. The physician quoted above focuses on expediency. A number of PICs could be applied for anxiety but he asserts they are more expensive than biomedical pharmaceuticals. The consideration here is cost as well as time.

The "medicate the life context" approach sharply contrasted with AM patient care. A notable difference between SUS and AM physicians was how they oriented themselves toward the patients and the idea of what was good or healthy and what was bad or unhealthy. SUS physicians referenced themselves as guides – experts in deciphering the cause and creating the solution. While they were faced with the growing challenges of medicalization and the abundance of misleading and misinterpreted health information on the Internet, they undoubtedly painted the SUS family and community health physician as a champion of the public and as an expert guide to patients. AM physicians leaned less on expertise and more on cooperation. The contrast lends some insight into the purpose of SUS as a boundary object between citizens and the state beyond its function to provide medical care (Farquhar 1994; Keshet and Popper-Giveon 2013; Shuval 2012).

SUS providers and managers often saw a lack of information, expertise or education as the root cause of unhealthy behavior. Physicians were then in a position and responsible to guide patients towards healthy choices. When queried about how responsive patients were to these suggestions one physician responded:

> I think that there are people who already come with an idea formed and are resistant. But I think if you have experience – it also depends on building the relationship you make [with the patient]. As the patient gains confidence, he realizes that you are doing what is best for other people, and this helps. Also, you

> cannot think that in the first consult that we will change everything in the person. And so, you have to have the tact to make the change gradually, but do not lose that focus of trying to construct this with the person. Because it is no use to merely deny the person's demand because that person will knock on another door and the thing continues. I think a lot of people over time that we get in various places I have worked – I still observe a lot of consumption of say Benazepril and I think a lot of those people I have been able to help. In the beginning you offer alternatives, explain why you are not reproducing [consumption], but in order to do this, oftentimes you are going to have to provide the medication until the person is weaned from it. Since I graduated, I've seen many fashions pass. I've seen many surgeries, hormone therapy, and use of benzioazepines. Now I see a lot of statin use without indication and proton pump meters; it's the big fad right now. Anyway, these are things that pass, right and we are there to try and contain those waves a bit.

This physician believes he is there to provide reason and appropriate care and to guide the patient's choices and behaviors. The physician is the expert guide in this interaction but one who has to be careful not to "scare off" the patient who may seek care somewhere else. While the physician is trying to exercise their understanding of patient care – paying attention to patient concerns- the physician is also trying to move the patient along the stages of change towards an understanding of health and treatment that aligns with the physician's own view of what is wrong, what is treatable and what is medically necessary. He references the stages of change model to health behavior in trying to get people to opt into care as well as what he deems the *right kind care*. While in AM physicians are still the medical expert in the room, the balance of power is mediated by treating the patients as experts on their own life context and lending a certain degree of credence to what they think is wrong. They do, however, withhold care that is not medically called for regardless.

Physicians saw medicalization impacting patient choices putting physicians in the position of trying to provide medically appropriate care, particularly since refusal often resulted in patients looking elsewhere for the treatments they wanted. This was notable in the overuse or little control of use of antibiotics and the medicalization of birth with 55% of women having surgical deliveries in 2013. The percentage of women undergoing cesarean sections in the private sector is extremely high at nearly 70%. C-sections are disproportionately popular in urban areas

(França, et al. 2016; Potter, et al. 2007). One physician thought 95% of the deliveries in the hospital where he worked were surgical. During the field research period, legislation was proposed to require physicians to record the medical justification for C-sections in order to prevent the procedure when it was not medically necessary. Physicians hoped that the new rule would make a difference since it had significant cost implications as well. Medicalization is a threat to the system because it is both expensive and challenges the authority and validity of the physicians within the system who offer different diagnoses and healthcare protocols. Doctors are there to provide care and their recommendations are to be followed. They have to walk a fine line between recommendations and conceding to patient demands even if they are unnecessary in order to keep them from seeking care elsewhere.

5.3 CHALLENGES IN SUS

Patients were the first to offer their critiques of Brazilian public services as well as endorsements for them in nearly every setting, particularly as questions over government spending and corruption came to a boiling point across the country. Brazilian physicians were generally equally forthcoming. While many acknowledged the limitations of SUS for example, they were careful to make sure this was contextualized by history showing how the system had improved overtime. They also contextualized it within the global healthcare landscape, asserting that the Brazilian public healthcare system worked better than most.

When describing the healthcare system and the challenges they encountered within the national network as well as within their own health posts, physicians often began with how "healthcare for all" regardless of whether one could pay for care was the beginning of a change

in consciousness for the country – a maturing and emergence from restricted freedoms under the dictatorship. Physicians talked about healthcare reform and the rise of SUS as a strengthening of people and a refocusing on community life. It was also cast as a rejection of the mercantile aspects of healthcare - thus some of the references to the U.S. healthcare system. Even the PNPIC had roots in the principles of organization, decentralization and expansion of access – a way to manage and meet the needs of 100-200 million people and amplify the approach to health to meet the wide array of health needs and views of citizens – to truly provide universal access. Brazil was not alone in this logic as PICs has been discussed internationally as a way to expand access (WHO 2013).

5.3.1 The challenge of making a national Brazilian Biocitizen in a decentralized healthcare system

Physicians cited many different challenges to the public system from multiple lanes including finance, political will, staffing and resourcing, associations of public system with the poor, high turnover rates of staff and more. Many of these challenges seemed to stem from certain perceptions of SUS itself. One physician, who was careful to state that his views on the subject was his personal opinion, explained that the healthcare system was often cast as "healthcare for the poor." He believed that the middle and upper classes, which made up the majority of politicians and judges or the "elite" of the country, did not use SUS or only did so when it was convenient. This created a dynamic where there was no personal commitment from "the top" where the power to intervene was concentrated and where decisions about resources and management were made. Things only would change when the elite invested in better quality healthcare for all. That way the "things would depend less on the moods of each ruler." The

idiosyncratic nature of the municipalities made the principle of decentralization an attractive solution for a country as vast as Brazil to address the specific health needs of each municipality. But the municipalities had a governing structure that changed with each election and with it the priorities for the system. This made efforts difficult to sustain.

Decentralization was designed to coincide with citizen participation where local municipal councils, state health and national health levels would interface. Every four years, these three levels hold a conference to formally meet but their influence on the politics – an inevitable factor any public healthcare system must contend with – is relatively small. This has implications for challenges with financing the system, which many physicians felt was not adequately suited to the design and objectives of SUS itself.

Funding implications were also tied to concerns over medicalization and its resulting cost to SUS. Medicalization posed an intriguing problem for SUS. On the one hand, it strengthened people's participation and use of the system. On the other, it was costly and contradicted the neoliberal mandate of self-care and responsibility for one's own health. One physician, who had gone on to become a specialist but remained close to family medicine and the PICs captured this in their description of the principles of the system:

> Thus, the SUS has three basic principles, which would be … it has several principles, but universality, which is access of the entire population. Integrality would be both treating disease and promoting health - making the treatment of the disease a form of health promotion. And the equity would be the person who needs more will receive more, and the person who needs less will receive less. This is the form that SUS was injected into the population and as it is in the constitution - that health is the duty of the State and law of the population. I think that this makes the population become every time in more of a passive position. "Ah the state has to give me health, it is the duty of the state to give me health," and this sometimes ends up creating some … not a kind of conflict but sometimes it fosters this process of social medicalization. One of the criticisms I have is this: our system, even though it is universal, it is not universal. It cannot currently reach everyone. And we are spending a lot on it, the budget that the government has to achieve its goals of universality, integrity and fairness is not enough and will never be. The more you invest in health, the more you spend. You see the example of the United States. And often decisions about where this money is being invested has influenced in what way the system will be managed. So these are points that are critical for directly influencing the user's decision process, where I go, what I go do. Generally speaking I find the system excellent. I work in it. I'm helping to build what is still under construction. But I have some criticism as to how it causes the population to position the State in front of health.

This physician references the surrendering of individual agency for one's health to the state – an expectation that by virtue of being a Brazilian citizen, that health and healthcare is owed to them by the state as a right of this citizenship – a pattern repeated when citizens make demands for access based on biocitizenship and the protection of biovalue (Greco 2004; Halse 2008; Petryna 2004b; Rabinow and Rose 2006; Rose 2001b; Rose 2006; Rose and Novas 2005). In an era of growing biomedicalization and financial challenges to sustaining universal access to healthcare across the nation, these influences on the choices Brazilian biocitizens creates a untenable feedback loop where citizens exercise their rights to participate, become more ensconced in the medicalization of life, and repeat the cycle.

Challenges to SUS also included what one physician called a "maturing of the country" and the redefinition of what it means to be a public servant, particularly in a time where corruption was (and is) such a ubiquitous topic. This paired with frustrations over bureaucratic constraints on how community health was defined, what constituted medical specialties, and the idiosyncrasies associated with each particular health post, had the potential to stop innovations in PICs or otherwise as resources and knowledge was choked out at the top. Every area had unique challenges to offering standardized service across municipalities, which varied greatly in size as well as in resources. Administrators at the Municipal Secretary of Health's office explained that most municipalities had less than 25,000 inhabitants making forming a dependable health network that could guarantee care in each city quite difficult. Municipalization and the interfacing layers of municipal, state and federal levels of the health system, made SUS dizzyingly complex. He explained:

> Since Brazil is a federation, the design of the public health system is the most complex design in the world, because it works by consensus among the three federated entities. It is highly centralized, because the

> money is still sent by the nation, although the prefectures have, over time, been putting more and more money into it. The state became empty, not knowing much what it was, what it did. But all decisions about the network, about the flow of patients, about all this must, in principle, be made by *collegiados* composed of: representatives of the municipalities, the state, and the federal government. So you imagine reproducing this on a Brazilian scale where they alternate, because all those there, municipal secretaries, state secretaries and health minister are politicians, and the positions also, inside the secretariat are political; and this alternates in four years.

SUS was designed to be permeable to social pressure by its citizens as a way to make it both dynamic and responsive to the needs of the population (Gragnolati, et al. 2013). But just as one physician explained earlier that those with the power to intervene were not personally invested in the system, this physician captures why such a complex system is still ruled by that Brazilian elite that may not have the same stake in the system as the Brazilian population at large. Each election had the potential to change the priorities, support and resources to the healthcare system. Municipal, state and federal elections also took place at different times making coordination and long lasting commitment to an agenda at every level for SUS quite difficult. Several physicians complained about previous mayors meddling in the system and enacting health initiatives that were neither evidenced based nor particularly useful while also being expensive. On the contrary, they also complained that certain programs or initiates that had been useful had their funding cut when support for them dried up when a new rotation of politicians came into office.

The tendency to shift priorities with the election of new political figures within municipalities also heavily impacted implementation of the PICs. SUS physicians who were interested in the implementation of PICs had to engage in a certain amount of negotiation for integrating the practices into health posts and polyclinics (and training professionals in the PICs themselves). The Commission on PICs was very active in this effort. Their efforts were complicated by having to validate PICs according to a biomedical or empirical measuring stick – a trend that has been well documented in multiple integrative healthcare practices internationally

(Adams and Li 2008; Cant and Sharma 1999; Fan and Holliday 2007; Gordon 1998). Due to many of the issues addressed in Chapter 4 on the struggle to implement AM in SUS for example, physicians had a difficult time making implementation of PICs a priority without the research or political will in some cases to push changes through.

5.3.2 The struggle between private and public practice

Other challenges to SUS came from the private health care and medical industry. SUS physicians prided themselves as being physicians of the people rather than a "doctor for hire" despite the fact that they were paid. Many physicians saw the values of private practice as being largely consumed by capitalism and incompatible with those of SUS. As one physician put it:

> You are going to have a conflict because if someone is offering care by virtue of "goodness" and another is doing it as an entrepreneur – "you pay me this money and I give you this service" at some point the entrepreneur will want to be "economical" with the money, with his payments to his workers or in the quality of the service he is offering. The more money he is going to save, he will put to the side for himself.

Despite the fact that many SUS physicians also have private practices on the side, private practice was associated with both the upper classes and an impurity of intention. Caring for those who could not pay for it had a noble quality that SUS physicians cited as a characteristic of the system itself and those that worked within it. This may have stemmed from the attrition the public system faced as physicians – especially specialists – shifted to more and more private patients in their private practices. Coordination of care, especially across public and private practices meant exams and services were duplicated and patients found themselves in a costly rotating nexus of providers unsure of where to turn. The sense of precariousness over the political and financial state of the country added to these narratives.

A key challenge for the public system was burnout, particularly in rural areas where physicians were few and far between. Before coming to Florianopolis one of the physicians explained that he had been the only physician for 4,000 people in a rural post. Florianópolis did not have this issue for the most part since physicians often wanted to live in large cities. This physician became a full time homeopath in the public system after a 3-year certification moving back to Florianópolis in order to practice. He had both enjoyed and struggled with his time working in rural areas explaining:

> Much of that time, one year I stayed there, I was the city's doctor, the only one. So I had to meet the demand for everything, anything. The city has no hospital. There is nothing and so everything came to me. It took a lot of effort because I was uncertain of what was going to show up at the door, anything was mine to handle. Yeah, there were serious things and not so serious things and death. All of these things were my responsibility; I was the doctor. I often had to interrupt a consultation because someone else was passing out outside. I often went with the ambulance, because I had to bring, sometimes in serious condition, some people to the nearest hospital.

Another physician explained that the stress of the job took a significant toll on the health of his colleagues:

> Most doctors I know are taking sleeping pills, pills to go to the bathroom pills for everything, for depression, for high blood pressure. My classmates are all sick. Nobody does sports anymore, nobody does anything else. Because you do not have time. I say in the graveyard you will have all the time of life right? No one complains in the cemetery; it's a silence; it's an endless peace.

Comments like these add dimension to the choices of physicians who choose to transition into private practices and who choose health posts with more support. The imbalance made meeting the needs of all of the municipalities, even more difficult to achieve much less sustain. Brazil's struggle to meet the needs of rural communities is not unique nor is the challenge of trying to get physicians to work and stay in these areas. But in such conditions, even doctors who did not mind living in rural areas rather than cities, had difficulty keeping up with demand and the stress. The government's attempts to bridge these gaps took the form of hiring Cuban doctors as part of

their *Mais Médicos* program, which brought approximately 4000 Cuban physicians to work in the public healthcare system in 2013 alone (Villaneuva 2013). Although some Brazilians complained that Cuban doctors were taking Brazilian's jobs, many patients admitted that this was the only foreseeable way to get physicians into underserved areas. Several patients encountered Cuban doctors in Florianópolis that were generally believed to be exemplary at basic care – something several SUS physicians who had spent significant time in the system, felt this kind of care was closer to the original mission of SUS.

5.3.3 Changing medical culture in SUS

Veteran SUS physicians often lamented the newer trends in medicine: the medicalization, specialization, and privatization that pulled physicians further away from what Brotherton showcased with his work on Cuban doctors and their role as exemplars of the "new man" (Brotherton 2012). When I asked these physicians whether these trends were a function of newer political influences, most attributed the shift to technology in medicine:

> No, this medical culture always existed. But it was never as strong as it is today. What started ruining medicine I think started in the late 60's or early 70's. That's where the doctors that treated you went extinct. Then they were just doctors right? Today you are a doctor but you are a doctor of what? People always ask. I say to these people, I am a doctor of human beings. If your body is still hot, I can attend you. If it is cold, I send you to the legal medical institute. But I will have a student who will only want to study the optic nerve. This is not a doctor, that's a technician. We should have a separate university for this, for what is medical and technical.

The idea of a division between doctors and technicians came up either as a complaint or as a solution to the struggle over medical culture in SUS. Some explained that as the demand for technical skills increased and became more involved, it would be necessary to separate technical experts and physicians as their own respective identities and professions.

Challenges and changes in medical culture and practice, however frustrating and from any of the many sources they stemmed from, were nearly always paired with a sense of indomitable will and commitment to improving SUS. This sense of history of the system – its roots in social liberation and democratization – gave a sense of hope for what the system was supposed to, did, and could still accomplish. There was a general consensus that those who believed in SUS would be there to make sure it had legs to walk forward and improve it with each step:

> In the last fifteen years we have expanded from about eight thousand family health teams to about forty-two, forty-three thousand, that is, you have one increase of five hundred percent. This government is fragile and I have serious doubts to what extent no matter how much the system is politically important – even the boycotts can leave the system skating. This is a picture that we have. In any country, you have moments that things are going well and have moments that do not go very well, only the future can tell. For me I came from a family of few resources, which depended on public health so much that we were in the queue at dawn to get an appointment for next month and today what we have, it has advanced a lot. Sometimes, those who do not know the story do not see the progress that has been made.

5.4 PATIENT DEMOGRAPHICS

Most SUS physicians who participated in this research worked in areas that had a wide range in patient demographics. Districts might house both upper and middle class families as well as students, and favela residents. Certain *bairros* were more homogenous however, and particular problems associated with that area such zoonotic diseases in places with higher concentrations of cattle or standing water, or either lower/higher socioeconomic status did emerge. Neighborhoods could be mixed in terms of their socio-economic status as well as quite homogenous. *Morro* neighboods, for example, had a reputation for lower socio-economic status. Unsurprisingly, SES and profession were tied to their conditions physicians ended up treating in these neighborhoods.

Physicians reported that middle to lower social economic status patients often sought care for musculoskeletal concerns from labor related activities like carpentry, civil construction or repetitive tasks like driving a bus for example.

Some physicians found themselves attending in health posts to primarily middle class Brazilians where others were responsible for lower income areas. All dealt with a variety in conditions, age and gender. While some described seeing the range of runny noses and chronic pain, other described combating HIV, STD's and tuberculosis, providing patients with prenatal counseling, sex education and dealing with individuals who were addicted to crack cocaine or other chemical dependencies. Some worked with prison populations or newly released prisoners, the non-ambulatory, the elderly, and transsexuals, homosexuals and transvestites, all of whom are particularly vulnerable in Brazil (Corrales and Pecheny 2010). Despite Florianópolis' reputation as being both beautiful and free of the violence attributed to larger cities like São Paulo, it also had its share of "*morro*" neighborhoods, where SUS physicians saw more young adults with mental health issues physicians associated with urban violence.

A great deal of the conditions that SUS physicians dealt with fell into four categories – routine care for children, hypertension, diabetes, and chronic pain. Despite SUS physician's assertion or assumptions that their patients were radically different or more diverse than AM patients, practitioners in both SUS and AM expressed similar concerns and observations about patient demographics and patient seeking behavior. Both AM physicians and several SUS physicians said roughly 80% of the patients that they saw had some sort of psychological complaint or primary concern. Psychosomatic illness and the medicalization of the population was a noticeable trend that doctors in both modalities noticed, referenced and were concerned about. These patients had a range of psychological health concerns including anxiety,

depression, and other manifestations of mental and emotional distress. These patients were often treated with psychotropic drugs outside of AM (although occasionally within as well).

SUS physicians also expressed concerns over the medication of children. One physician explained that he saw many children who took psychiatric medication and felt the trend was both unnecessary and a movement encouraged by developmental psychiatry and parents who had been medicated themselves. Other physicians echoed his concern in their descriptions of patients' demands for exams and medications that were not medically necessary. Physicians, like the one quote above, often attributed demands for inappropriate care as an education gap:

> It is very difficult to guide a person with some treatment or even understand what she needs, or what she wants to talk about when she cannot express herself very well. And I see that education makes a lot of difference in that. Being able to read and write and to have studied a little, it makes a lot of difference in the person to be able to express himself, to understand the treatment, to do the treatment, to take care of his health.

The lack of education was tied to susceptibility to false claims made through mass media as well as the commodification of health:

> It is precisely the issue of medicalization, of excessive consumption of medicines and therapies. Also it's a culture established by the mass media, by medical practice itself, the most common thing is that those who have access to health resources in Brazil ... is as if it were a commodity. So if we sell a lot and we are in public health, we also minimizing the needs, not necessities, the demands that are not often logical, from that population. We also have to deal with the issue of resources, to optimize the resources you have, not to spend it on consulting, procedures, collections and other things. This is something that is deeply rooted in our approach, this concern This is an exhausting thing that often conflicts with the immediate desire of the person.

Several physicians saw the proliferation of demand for exams as a side effect of too little time in a patient visit rather than a lack of education or media and health literacy. Several SUS physicians noted that AM doctors did have a high degree of success with patients with lower health literacy – a difference they largely attributed to AM's extended consult times. Many of the SUS physicians recognized the importance of understanding a patient's life context and linking

treatment to their lifeword as well (Barry, et al. 2001). But with limited time, it was difficult to do particularly if there was a line out the door of patients waiting to be seen. Patients were looking for answers and to be attended to. In the absence of time with a physician, some sought medication, exams or various specialists instead, leading patients down a "rabbit hole" one SUS physician called "social medicalization." AM patients often complained about this cycle and cited it as a reason for their exodus from SUS.

SUS and AM practitioners also noticed more women of every age and children seeking medical attention than men who often went if "*one of their women dragged them in.*" This was more pronounced in the PICs but still a noticeable pattern for almost all SUS physicians as well. A common explanation for this pattern was that because of cultural norms, men were less likely to seek help than women unless they were in mortal danger or unbearable pain. They generally only came in when they felt very sick, and were resistant to help or non-complaint, which often made their cases more complicated and difficult to treat. As one physician joked "*it's easier for them to order glass of cachaça than to ask for help*." Physicians also stated that women were also more likely to accompany their children or elderly relatives to the health post.

With the exception acute issues like broken limbs, heart attacks and so forth, patient demographics seemed fairly similar between SUS and AM doctors from their reports in demographics and patient seeking behavior. While AM physicians likely saw patients from a wider SES spectrum, there were a number of patients who were seen on a sliding scale, or who saved up for considerable time for AM visits. Other regions of Brazil, like São Paulo were also home to AM initiatives that began in *communidades* like Monte Azul.

5.5 SUS PHYSICIAN PERSPECTIVES ON THE PICS AND THE PNPIC

5.5.1 PICs and fashionable medicine

Practices like homeopathy have existed in Brazil and public healthcare – albeit isolated instances- long before SUS or the PNPIC came into being. The inclusion of "integrative and complementary" practices into SUS aligned with the system's original harkening to principles of universal comprehensive access to the health services; the promotion of equity; decentralized management; and social participation put forward by healthcare reform. It was also tied to the recapturing or rediscovery of traditional medicine to not only improve access and health outcomes, but to also participate in and create an authentic Brazilian medical practice both unique and illustrative of the county and the new Brazilian biocitizen. PICs also had important cultural and market impacts as well.

With the advent of the PNPIC, what had been medical traditions isolated in several communities or modealities relegated to "home remedies" has in some cases, become fashionable and fetishized partially through the greater access the PNPIC has provided. Several traditional herbal remedies or "folk" remedies have become more expensive than designer drugs like benzodiazepines. When I inquired as to why medical traditions that had been used for years in Brazil and that are not expensive to produce had become expensive, the answer usually given was that natural remedies had become fashionable.

Similar trends could be seen across the island whether it was the "discovery" of more rural areas by wealthy vacationers and or developers to settle in the "traditional" neighborhoods of the south or even the of traditional foods. One example of this was *Tainha* – a local fish caught in the winter months that has historically been a food source for lower SES

neighborhoods and fisherman. Fishermen would spot the schools from the beach, row out together in a long wooden canoe with a net to circle the fish and then send a fast swimmer to shore with the other end of the net. Neighbors on the beach would help drag the heavy nets in catching scores of fish at a time. Participants usually received a fish or two for their efforts. Tainha, however, has come to be a marker of authentic Brazilian culture on the island, and to consume it is to posses this authenticity. Now six families own the permits to fish and often do not share much if any of the catch with helpers on the beach since they can get $R30 for each one at the local market. Tainha have become too expensive and rare as commercial fishing further south catches most of the schools before they can even reach the island. What was once ubiquitous and consumed by those of lower SES has become fetishized and consumed by the middle and upper classes. Both medicine and artisan tainha fishing illustrate how the valuing of the "authentic" mainstreams certain practice, while also making these practices inaccessible to the sections of society that historically depended on them.

The fashionable aspect of the traditional is important to the island as hundreds of thousands of immigrants flock to its shores for summer vacation although a significant amount of them have ended up staying. Many residents from São Paulo, for example, resettled in Florianópolis. Often students came to the island to study at UFSC only to stay and call the island their permanent home. Those that had families with long histories on the island often resented this influx as it ate up space through rapid development, and healthcare resources. In this fluctuating cultural climate, traditional practices like medicinal gardens, or tainha fishing was a way to demonstrate an authentic belonging that outsiders reproduced in order to possess a similar belonging.

5.5.2 Prescribing PICs in SUS health posts

Despite the fashionable aspects of some of the PICs, doctor "shopping" and the seeking of PICs was something that few physicians inside or outside of SUS reported often. While some physicians explained that their patient's came with demands for allopathic medications, procedures or exams they did not need, when it came to PICs, most SUS physicians had to suggest these alternatives to their patients (unless they were well known for their work in complementary therapies like herbalism). Several physicians expressed their reticence to prescribe certain PICs if they felt the empirical evidence for it was lacking. In some cases, positive personal experiences with PICs boosted their confidence in prescribing them, however. Physicians expressed having to negotiate with patients to use PICs especially when these substances were less potent, more labor intensive or time consuming to use and be cured. These negotiations had better success if the biomedical medications they were trying to substitute out were going to be used for a long period of time and/or was habit forming. Sometimes physicians wanted to offer certain PICs but needed to have extended conversations with the patient in order to explain them, or block out more time to treat patients using PICs. If the physician did not have the time, then they reported being unable to make the recommendation to use PICs within that consult. One physician who practiced homeopathy privately when she was not at the health post explained that in her private practice, they could delve into the history of that patient during an hour long session. In her words, the extended time allowed the physician to "rescue" the patient from their predicament. A consult of that length in the public healthcare system proved difficult to do.

Physicians often legitimized their approach through evidence based interventions or studies so often associated with biomedicine. At the same time, most of the physicians expressed

a direct or indirect critique of the limitations of a biomedical paradigm in its approach to patient care as well as an assertion that the healthcare system had moved beyond such limitations and paradigms.

> As the system gains more followers, more soldiers as we call them, more professionals, more people are collaborating. And since this reform of the system and the construction of a more effective, more humane, more accessible system, it also went beyond the biomedical paradigm. So that left the fertile ground for this world-changing, paradigm shift. Let's put it like this: it's more of what Kuhn tried to give us, knowing the limits and such of scientific knowledge. It is a fertile ground for this worldwide movement to germinate here. That people could within this already established framework that already had sufficient openness, that already had a broader look on health and incorporate other medical rationalities and other practices in a fuller way. So it has to do with the historical process in Brazil. The very concept of health that was defined by this ordering system is broad enough to incorporate social determinants, work, income, and the environment. And then all these things were necessary for us to have this national policy of integrative practices. The limits of other practices were recognized.

In this sense, PICs were an opportunity and a benchmark to show the uniqueness an in some ways the evolved nature of the Brazilian healthcare system. Narratives like these were certainly not shared by all physicians, some of whom had more or less close relationships and experience with the PICs. Many physicians framed their relationship to the PICs as just that – complementary. They expressed sentiments of avid researchers and their interest in the PICs seemed to stem from this research focus. Often interest was framed from the perspective of trying to prove or test whether one of these practices really "worked." Certain practices were also more or less known for certain types of ailments and became largely associated and used with patients who presented with those associated ailments. Acupuncture was particularly popular especially since Brazil has the only residency program in acupuncture outside of China. There was still some ambiguity in how integrated or useful physicians perceived PICs to be within SUS, however. As one physician explained his use of PICs in his practice:

> And, in relation to integrative and complementary practices, I always try to take a complementary approach. For many things they work well, when the patient has osteoarticular problems, acupuncture may be great, but if he does not like needles, it won't do. Then you'll have to use a conventional physiotherapy approach. But I think I'm quite traditional still. I do not think these, these therapists have a stronger medical

> background [than I do]. They have conditions they deal with very well, because you may be putting this aside in terms of diagnosis that might prevent or address something more important faster. So I think we need to respect them, use them, but also recognize the limits and timing of a training so that it can be appropriate. Not that the biomedical model does not cause iatrogenesis; it causes a lot. But we can also have a lot of iatrogenesis from the other as well. What we want is not iatrogeny, we want less iatrogeny.

Here PICs are useful in the sense that they may bypass some of the diagnostic hoops and side effects of biomedical treatments yet he is still unsure of their overall value and place in practice. Keeping them complementary assigns these practices a place that he seems more comfortable with. The physician pivots to these services but only if necessary.

Placing PICs as the final line of treatment if biomedicine failed frequently drove acceptance for PICs. Pain management was one of the most notable examples of this. One physician, who began applying acupuncture to his orthopedic patients, said 80% of the problems he could not solve, he could treat successfully with acupuncture and so he had decided to pursue the practice further. Failure to improve the health of patients was cast in several different ways, however. Some physicians referenced the failure of biomedical models to address breast cancer etiology and the need for social support for example. While they did not always comment on the efficacy of PICs there was recognition of the important gaps complementary and integrative practices filled in terms of the social and psychological wellbeing of patients. The Spiritist hospital for example had everything from a "talk therapy" like model to the laying on of hands by volunteer practitioners. While SUS physicians were careful not to endorse or dismiss the practice entirely, they did acknowledge that for a patient suffering, just having others lay their hands on you in solidarity and support was meaningful to the patients. Physicians who actively practiced the PICs also explained that being able to use a different approach to patient care was helpful and at times a relief. This physician explains she was frustrated with the limitations of "traditional medicine," – in this case biomedicine – and found homeopathy to be a useful tool:

> I've always liked homeopathy, but I think it was more a discontent with traditional medicine. There are many things that have no answer in [bio]medicine. It's very good in terms of diagnosis. Some things have extremely effective treatment and a lot of other things have neither answers nor treatment, and then I started to be interested in getting another type of treatment. I think homeopathy gives us other therapeutic opportunities mainly in these situations, or cases, diseases that have no treatments such as palliative care in traditional medicine ... And homeopathy, it contemplates another overview of the patient, of people. So you take into account her previous history, social history, cultural history, her trauma and childhood - things in the person's life, the individual characteristics of it and there the illness is just another piece of information; it is not the focus.

Here, the physician is also using the same last resort treatment logic but it leads her to referencing an approach to patient care that is much more akin to AM and the time and focus that one could provide patients in a different modality. She also explains that this "other" approach to patients is useful not only as a last resort but as a way to frame patients within their own context rather than within pathology. Physicians like this one were champions for the PICs and donated their time to helping make the practice more accessible and mainstream working with the Commission to fully realize the PNPIC in Florianópolis. The challenge was to insert PICs directly at the health posts so that they were something intrinsic to SUS rather than a separate entity tacked onto it.

5.5.3 Physician education and integrating PICs into SUS healthcare

Integrating the PICs into SUS meant making these services accessible and known to the Brazilian public, which might have experience with some but not all of these modalities. Normalizing these services for specific ailments like acupuncture for pain, auricular therapy for headaches, and so forth, created intuitive lanes or expectations of utilizing the PICs for patients and prescribing for physicians. In order to meet this kind of demand, SUS physicians needed training. The insertion of PICs into SUS was largely in the form of introductory courses to the

practice itself where SUS physicians could take compressed courses – usually 8 weeks – to learn the basics of one of the medical rationalities included under the PNPIC. Training enabled these doctors to then practice any of the PICs within their health post. In general, the relationship to specialization or medical specialties was quite different than the U.S., which facilitated them being able to practice modalities they were not necessarily certified in. SUS physicians with no AM training could technically prescribe AM medications for example. Below, this physician explains the relationship between education, specialization and ability to practice PICs:

> Yes they can practice. Here in Brazil, the doctor once he has graduated, he can do any procedure, from neurosurgery to prescribing medication, giving birth - any medical procedure. The doctor is able to do this. He does not need any extra training. What he cannot do is call himself an expert [without certification]. Family doctors, especially here in Florianopolis, they have very good training, very strong; so they can do small surgeries and they do outpatient procedures. If they do that, they could apply some acupuncture techniques.
>
> We did some courses for the health network, for acupuncture, for needles. So, you use techniques that are in acupuncture, but that does not necessarily require a two-year training. It's so that you start doing it in some patients, and that we know these practices are beneficial and that they will cause practically no damage or at minimum it's an extra pain, a needle that made a bruise, right? So, for example, I can teach you to do some techniques to needle some points for some types of headache by location, without necessarily a "Chinese" diagnosis.

The physician here skips theory and instead directly emphasizes practice. Many practitioners of PICs, AM included, would likely object to the idea that practice without command of theory is problematic. While the courses gave post physicians a working understanding and basic tool kit in one or more of the PICs, many of the physicians interviewed had sought formal training in things like acupuncture outside of the system's 8-week programs for additional knowledge and expertise. Most physicians, however, seemed confident that health post physicians could apply PICs well with the assistance of the short trainings although not all were so confident that this applied to all of the PICs. AM and homeopathy are not conducive to such a compressed format since they both require extended trainings. A few private practitioners argued that acupuncture also required years of practice and learning and that what was applied in health posts lacked the

traditional Chinese diagnostics training. A small number of physicians found the expedited training concerning. One SUS physician who was also a homeopath explained:

> I think training is important. Because otherwise you run the risk of doing sloppy homeopathy and I think poorly done homeopathy is dangerous. And also I think it is something that has happened already and happened from the beginning of homeopathy. Many things are distorted, are made in ways that are not correct. People learn and begin to deviate a bit and continue to keep the name homeopathy. So in Brazil a lot, a lot of people talk about doing homeopathy, but the way I see it, very few do it. Homeopathy has a very famous name, but what many call homeopathy has lost its essence. It is unfortunate because this hinders homeopathy.

Questions of purity aside, there were noticeable power struggles across the board around PICs. Some wanted to keep the practice "pure" requiring the full training. Others found themselves trying to implement the course to socialize doctors to these other modalities fighting an uphill battle with the "purists" worried about cooption and dilution, as well as with politicians and competing priorities. "Municipalization" further complicated this struggle with rotating gatekeepers with disparate interests and agendas.

The PNPIC was a policy rather than a law. This meant that implementation was at the discretion of local governments. All that the policy achieves is the authorization of public services to include PIC practices and medicines within SUS. But as one physician put it "*each municipality has to adapt this to its reality*." It is the municipality that decides what specialties are a part of NASF and which professionals and specialties are the most important for the municipalities' needs (Brazil 2008). This tends to tip the scales towards psychiatrists, psychologists, social workers, pediatricians, nutritionists, physical educators and physiotherapists. With the healthcare system already stretched to meet the needs of its citizens, services like dermatology were higher priorities than the PICs in many cases.

SUS physicians with experience and interest did have the growing medicalization and need for expansion working in their favor. It made garnering political will a slow but steady

pursuit for practitioners looking to help carve out a more sustainable place for PICs within SUS:

> So we've been carving out the space with the Commission since 2006, digging, digging, taking courses, giving resources so that people can do something that interests them. But with that we were gaining strength right? So today it starts getting clearer, I think, for the managers and other medical colleagues. Of course it's not that I'm getting rid of physiotherapy; we need a physiotherapist. But we cannot send all the people with pain in their shoulder, the right shoulder, the left shoulder, the elbow, the foot, the other elbow, the knee to the physiotherapist, understand? Half of the population that sleeps poorly, lives poorly, works poorly, right? You cannot send them all to the physiotherapist. It's impossible and this will never solve anything, because you will not hire one physiotherapist per person. This is absurd, right? So I have to have other things to solve osteo-orthopedic problems, for example, acupuncture, gymnastics, physical activity oriented, things right? So we're getting there.

5.5.4 Why PICs and why "now?"

PICs became important due to financial, practical, and political reasons. Some physicians identified these factors separately or only one or two while others painted a picture where traditional medicine and cultural renewal was tied to capitalism, dissatisfaction with biomedical treatments and approaches to patient care and the overspecialization and mechanization of medicine itself. The glue that tied most of this together was the movement by the middle class and the medical class, which pushed for evolving care and contributed to a new niche market. When explaining the market aspects underpinning the inclusion of PICs, this physician explained:

> And people started being dissatisfied, but mostly, I'm talking about the middle class. This is a movement of the middle class - a movement of middle class and medical class. Medical class in the two-way sense, first those who really wanted to do something different because they were more alternative, and then others who saw in it a potential market, a new market. Many orthopedists began to do it because they began to have too many orthopedists. Now they can be an orthopedist and an acupuncturist. It's not the rule, I think most, in the end, did it because, because some believed in it.

Despite the fledgling nature of PICs in many places, other SUS physicians acknowledged the growing trend not only as a result of PICS's becoming fashionable – a reinvention or rediscovery of traditional modalities – but also as a result of shifting patient priorities and rights

claiming. Exercising choice was more than indulging the whims of a middle class that wanted to consume what was fashionable in medicine. It was a way for citizens to participate in a social movement:

> Brazil, in its various ways has a social movement, a community movement, a movement of people to seek things like that. It's become a very big claim, especially in these last years, thirty years there, after the dictatorship and such. People claim "Wait there, I do not want just medicine, I want other things, I want my request to make sense; I want the plant that I use to make tea." Anyway, then I think it comes from here and through popular pressure too. I think that also made it happen.

In some cases, SUS has become quite responsive to these requests and had things like medicinal gardens that enabled patients to take home plants rather than medications. But the popular pressure applied to SUS may also stem from the state of SUS in certain areas of the country where the healthcare system struggles to serve their residents. One SUS physician in Florianópolis learned most of the herbal remedies from his patients while working at a remote health post where most people relied on their own medicinal gardens since the health post was not open all week long and not able to serve everyone when it was open. Medicinal gardens were still an integral part of home care especially if other forms of care were not reliably accessible. Expanding care through PICs was something the World Health Organization advocated for, which has also encouraged Brazil to continue pursue integration to expand care (WHO 2013). The physician here explained how he believed Brazilian healthcare had helped set the international stage for the inclusion WHO was advocating for:

> The way the health sector was organized / mobilized had a very great influence on the ideas of Alma-Ata. This is north, right. This health policy for all, complete attention, valuing popular knowledge, valuing ... complementary medicines. This has been very present the whole time since the formation of SUS, that is, this is something that has been growing the whole time. I think that sometimes the very deficiency of the system, that it still has many gaps, many difficulties, makes the people themselves, a large part of the population, still use complementary techniques, complementary models with professionals who have a freedom to be able to exercise these … I would say they are techniques ... medical models, let's say, if the word serves.

5.6 SUS PERSPECTIVE ON ANTHROPOSOPHIC MEDICINE

5.6.1 The uneven inclusion of AM

Despite its inclusion in the PNPIC, AM was largely not included in SUS in Florianópolis with the exception of several AM doctors who worked at health posts as well as private practices. Outside of São Paulo, Belo Horizonte and Juiz de Fora, AM was considerably less well known or widely used compared to homeopathy or acupuncture for example. When I inquired as to why this was the case despite the national policy that allowed for its inclusion as one of the medical rationalities that could be aligned with SUS, there were several answers although no one seemed to be entirely sure.

The first assertion was that there was not a great deal of offerings in AM medical training or certification in the city and that The Clinic itself was not all that easy to find. Most SUS physicians commented positively on AM techniques and quality of care and believed if the practice were more accessible, that other SUS physicians would more readily take it up. This raised the question, however, whether AM was conducive to an 8-week training course. Practitioners of other medical forms like Chinese medicine, could both appreciate the value of including pieces of their practice in the system as well as share concern over their practices being coopted and "watered down" or practiced by people with considerably less training that they had. After taking 70 hours of AM training myself and only being two thirds through the first phase of training, I found it difficult to believe AM could be distilled to an 8-week course or even that there were "basics" that SUS physicians could train in.

Physicians who had taken the 8-week courses seemed to feel confident that they could practice what they had learned although some took up studying the specializations more

thoroughly on their own. The idea that someone should have to take a 2 yearlong certification course to administer an acupuncture needle struck many SUS physicians as obstructionist and unnecessary. While most agreed that SUS trainings should not bestow the title of "specialist" on those that completed them, they also expressed that the level of training to become a specialist was unnecessary to practice some of the basics and that some of the hallmarks of these modalities such as alternative diagnostics or extended appointment times (45 min or so) were also unnecessary to including them in SUS precisely because these practices were still complementary rather than primary.

While most physicians who practiced PICs felt that the training they had received was sufficient preparation to practice, they did acknowledge that AM in particular was difficult to integrate into a similar formula for a variety of reasons. The most prominent barrier was the "vision" anthroposophy had of medicine, the human being and patient care, which was tied to perceptions of the human being and health intervention as more than the manipulation of matter, which many saw as spirituality:

> I think it is like this: the anthroposophic medicine that is already included, is more distant from really being included because it involves the question of another vision. Anthroposophy I think in this sense, I see as more complicated to be accepted because it involves the spiritual question, and this for some people cannot be taken seriously no matter what. Because it is a very subjective thing; you do not involve spirituality. It makes sense to me, and I personally have sought it for myself, for my health, right? And I want to be able to practice it later, but I do not think it's going to be in SUS. I do not think I'm going to have that space. When you involve the question of spirituality, there you already take away the credibility for, I do not know, sixty to eighty percent of health professionals. If you think this could be compatible so to speak, you cannot include spirituality in your approach.

Several physicians had experience training in AM as well as being AM patients themselves. One SUS physician I actually interviewed at The Clinic after one of their appointments with an AM physician. They expressed a perceived impossibility of practicing AM in the public healthcare system due to the time constraints and patient loads required in addition to some of the medication and access concerns. One physician explained that they felt becoming

an AM physician meant transitioning to private practice for many of these reasons and she therefore did not practice AM in order to remain in the public system and had cut her AM training short.

The rejection of AM and its assumed incompatibility with the public system exposed several inconsistencies particularly since AM physicians were practicing in the system in the area and these SUS physicians knew that. In other states, AM physicians had been given the leeway to work in public health posts with longer appointment times as well. This physician who had cut her AM training short also explained her work in the public system gave her more freedom in requiring patients to return and for longer appointments than even AM physicians had:

> Within the Health Unit, at least here in Florianopolis the experience is really multi-professional. I am always discussing cases with a health agent, with a nurse, I take a case for the psychologist, I argue with the psychologist. There is a discussion of the story where the center of attention is the patient … well it is still the doctor, but inside the health unit we really have the opportunity to do multi-professional work. From acting as a team, then every week I sit down with the health workers: are they going to visit? How is this patient? What do you know? What happened? Oh, the son of Dona Fulana uses drugs and that's why she's so nervous ... I do not know, so this information is sought right? And another thing is that we make affective bonds with the patients - with some people you make a positive bond and with others not so much, and others that you keep … you want more distance … but anyway I think we have the opportunity to really be interested in the patient right? And in responding to the needs of each one within what is possible. If we work in a unit that does not have an overload of work, this becomes easier. We give these individual answers unless you cannot stay with the patient. Today was crazy, I stayed two hours with the patient ... Two hours! Yeah, I was in luck that the medical intern was there, so she stayed put, made the other appointments and she called me when she finished for me to check the closing of the consultation, see if everything was fine, but that particular patient I stayed with him for two hours.

Extended visit times were made possible by toggling back and forth between patients. While the diabetic patient referenced here had his sores wrapped by the intern, the physician attended to other consultations for example. While she was able to do this because of her assistant, it showed that exceptions to the classic biomedical model in SUS were in fact quite possible. Furthermore, she deemed this extended appointment necessary since the patient was only 28 years old but had diabetes, neuropathy with ulcerations on his feet and also had contracted syphilis for the second time. This physician also explained that the elderly often required

extended visits as well because they usually had a number of health concerns to address and did not always understand the treatment plan readily.

5.6.2 Contrasts in SUS and AM care

In order to reconcile the cited barriers with examples of flexibility, one has to recognize the diversity in health posts. The diversity in resources, and arrangements in the Brazilian public healthcare system is reflected between states down to their neighborhoods. What one health post is able to do is highly dependent on who is on the agenda for the day; the number of emergencies that show up and the resources the health post has been given. This means that the flexibility of physicians to make adaptable arrangements based on demand such as needing to spend extra time with an elderly patient – are largely dictated by the influx of patients. While there was a proposal to limit the number of patients to 3,500 patients per healthcare team, several physicians complained that the number was often significantly higher raising the demand on healthcare teams. Teams coped by working together adding certain patients to other practitioners' agendas if they had concerns better met by someone else or easily treated by the nurse. They called this approach *matriciamento:*

> Sometimes, of course, we run over and we end up attending patients very fast. When everything is running very fast we might forget about ... "ah I forgot to do such and such a thing with that patient." The patient will come back though and you remember "oh I was going to refer him for ophthalmia consultation, I forgot in the rush, ah the next time he comes I do this," I'll remind him. Or sometimes after the patient goes away I remember "ah I was going to ask for an examination and did not ask", then I go there I open the medical record and make the examination request, understood? Or I make a referral ... We have inter-consultations too, so the patient is being attended by the nurse if she is a pregnant woman who is doing a normal prenatal visit with the nurse, or if there is a complaint there the nurse calls me and I go to the office, consult the patient there and then I decide what to do. I'll make a prescription for example. We handle most things that we have in unity - what we call *matriciamento*.

This approach has similarities for example with AM's cooperative care approach with physicians and multiple therapists all working together to treat one patient yet it provides contrasts to how care is coordinated and conceptualized by AM physicians. The hustle and bustle of the health post is exceedingly different than the atmosphere at The Clinic even when it is at its busiest. Referrals are made often in-house, which means the discussion time is also internal. There is tranquility at The Clinic that is built into the physical environment and space itself.

There were a number of other ways that SUS physicians and their healthcare teams managed the treatment of their patients. Some of the patient education and self-care education for diabetic patients for example, was handled by the diabetic interest group at the post in what could be characterized as a biosociality (Rabinow 1996). These groups met regularly to share challenges and resources. There were several different kinds of groups designed to do everything from patient education on hypertension to offering yoga classes. For those patients, like the 28 year old diabetic she spent 2 hours with who required in home care or who presented with complications (from non-compliance), there are other mechanisms that physicians use in order to reach these patients:

> Well, I can go to his house to make a post-hospitalization visit, to know what happened ... Rescue this patient so he can continue the treatment, and does not abandon it, and doesn't let it happen again. So it's possible to do that right. Inside this system, we have a system that we do home visits. All of my patients that are bedridden are registered, right? I have an annual visit planning meeting, so I know "ah that month he did consultation with cardio, this month I went to his house, that month he took it, ah now I have to go back there, right." I can plan the visits together with the health agents that always go together. When the nurse is there, she will also follow up. We have meetings with diabetics to pass on information so we can have a little better control of them.

There is an overriding sense of making sure vulnerable bodies are also disciplined ones in this physician's statement (Foucault 1963; Foucault 2010). Home visit teams are there to make sure the health post is able to reach their patient even when the patient cannot make it to the health post itself. Care and the agents of care have an extended reach into the homes and life context of

patients "*to have better control over them*" and to make sure they continue with the treatment or "*not let problems happen again*." She also uses the terms "rescue this patient," which illustrates the way SUS physicians orient themselves towards their patients compared to AM physicians (see chapter 4).

Other support agencies like The Family Support Center, NASF (*Núcleo de Apoioa Saúde da Família*), *Centro de Atenção Psicossocial*, specialists at the polyclinic, and the rising availability of digital consultations as well linking up of electronic health records with the UPA, all contributed to a model of care that utilizes multiple inputs that do not necessarily engage with the patient themselves but rather the family physician who acts as a nucleus of care and the manager of the treatment protocol. One physician expressed the desire to learn more about how to practice each specialty so she could treat patients without relying on the specialist (even the ones that did make visits to the health posts to coordinate care) because the patients "were hers." She attended to patients alongside the psychiatrist with the intention to be able to address any issues the patient might present with later when the psychiatrist was not there.

> The more I learn about psychiatry, the more I learn to handle psychiatric medication, and I can manage patients without being so dependent on the psychiatrist, because the patient is not hers. The general practitioner is the one who manages the care. So the patient is not the psychiatrist's; he is my patient. I do the consultation along with the psychiatrist because I need to learn more about psychiatry and about that particular patient right, because theory is practical theory, because every patient has its characteristics and the psychiatrist will help me to shed light on that patient, for us to know how to handle that patient. It is not just a question of medication, it is to understand this context of this patient.

Here the ability "to handle" or "manage" the patient is something that needs to be learned from the specialist. The SUS health post physician becomes more than a "jack of all trades" in terms of the variety of patients they see; they also become a lay specialist of sorts – the nucleus of care. Unfortunately, this model does not always mean care is coordinated as shown in the chapter on patient choice.

5.6.3 SUS physician perceptions of AM care

In many ways, SUS physicians saw AM practitioners the same way they viewed specialists who transitioned to private practice. AM was often viewed as healthcare for the wealthy because of its association with private care and private care's association with upper middle class Brazilians and SUS with lower income Brazilians. While this strict divide held notable and numerous contradictions, it also enabled the persistence of a belief that AM practitioners were not interested in being a part of SUS because they had carved out a lucrative space for themselves in private practice and rejected the "collective good" of public health. As one SUS physician asserted:

> The professionals of anthroposophy that are in Florianópolis all work privately - just for the individual. They are not interested in the public health network. And today in Florianópolis health policy is such that you go to work in a post eight hours a day; there is no other way. So, I'm a homeopath but I cannot just do homeopathy [in SUS]. I have to do home visits, attend all patients - everyone and anything. If I do, I'll do homeopathy, understand? It's already regulated in the municipality that I can reserve one period per week, one or two to do homeopathy, for example. Or do acupuncture, or to make anthroposophic medicine. Then we doctors and network nurses can book one or two periods in the week to do alternative medicine. The problem is that the demand is high.

There were certainly AM doctors who worked 8 hours a day and who did home visits and attended the same range of conditions as their SUS counterparts. They were also just as concerned with public health as their SUS counterparts. The exclusion of AM and the perception of remaining separate came largely out of the lack of a widespread 8-week training in AM medicine for health post doctors. Homeopathy ran into similar issues trying to balance being included and maintaining the quality and approach to care that many argued too far longer to teach.

> In Florianópolis, you will not find homeopaths open to saying "let's give a basic homeopathy course or some basic principles for family doctors so they can prescribe some things without being homeopaths." They are resistant in order to reserve the market. So, I guess it all depends on this. Also today in certain

> cities you have more therapists or therapeutic opportunities for one medicine or another, right? From one practice or another practice. And from anthroposophy, as far as I know, we may have a shortage of professionals, a lack of use by the population. It is not very common culturally. There is no group that pulls it inside the secretariat. Soon if you have a secretary of health that is anthroposophical, it will pull in an anthroposophic policy.

While this argument casts the concerns of practitioners worried about having their practices being coopted as one of money rather than quality or integrity of the practice itself, it does capture some of the important differences that has made AM quite well known and integrated in areas like Belo Horizonte while remaining relatively absent in others. Belo Horizonte has had an integrative policy for 21 years before this period and AM was a vital part of the modalities included. When discussing this with the head of the ABMA and other physicians and healthcare mangers who came to the summit celebrating the anniversary of this policy in Belo Hortizonte, they explained that it was through the physicians who had roles in the Ministry of Health and AM, that made this possible. It was somewhat of a contrast to see healthcare managers for the whole state passionately advocate for the continued expansion of PICs in the system sometimes with more fervor than the practitioners themselves.

The level of integration also impacts and is impacted by the degree to which physicians are exposed to other modalities in medical school. Many physicians had no contact with AM in medical school and without the training modules, remained relatively removed from the practice itself. AM physicians were in fact working on making information on AM available in an online module to socialize this modality around the time that this fieldwork period was finishing. One physician I interviewed had seen it and was pleased to see that the information was "being disseminated" and that it also included concerns over zika, dengue and chronic pain – all things that were at the top of the list of concerns for SUS physicians.

Several SUS physicians I spoke with were starting the first level of AM training on their

own, and were eager to make it a part of their public practice despite the practical and bureaucratic hurdles involved. After all, there were AM doctors who also practiced in SUS in Florianópolis, and had been for quite some time. These doctors had attempted to bring AM to public service as more than an individual offering and had run into wall after wall to realizing that effort. Their efforts had been either forgotten or remained unknown to many SUS physicians who simply assumed no one from AM was knocking on the door. AM physicians were passionate about public health and SUS physicians beginning in AM found many of the messages of public service and patient centered care that was widely talked about in SUS very much made a part of practice in AM. Newer generations of SUS doctors taking the training were able to recognize the common ground between the two modalities, however.

While AM physicians were at times eerily similar in the phrasing and approaches used in their narratives about patient care or why they started in medicine, SUS used many different themes to describe the system and even more to describe their approach and the patterns of healthcare seeking behavior of their patients. SUS physicians were fairly consistent in their vague objections to including AM. AM was considered an unsustainable practice in SUS because of the time it took, use of non-biomedical treatments, or because of its "alternative" vision of the patient and patient care that was non-materialist. All of these reasons had notable contradictions within SUS physician's own narratives about their own practices. Sometimes they took more time with patients, sometimes they wanted to know patient context and sometimes they wanted to provide patients with less costly interventions like lifestyle changes or PIC remedies rather than medications – all things AM physicians do and champion.

5.7 SUS PHYSICIAN'S VIEW OF CHOICE

SUS physicians believed patients were drawn to PICs because they had family experience with them, saw advertisements for these treatments or were simply interested in the utility of treatments that in many cases had less side effects and were easier to use. One physician explained that a patient of his had come in with lower back pain so he had prescribed physical therapy, some recommendations for posture, analgesics and anti-inflammatories. The patient returned still suffering from back pain so the physician offered acupuncture. Within 30 minutes, the patient had no more pain and had yet to return to the post with back pain. Being able to offer alternatives that were effective and less costly made some PICs attractive in cases like these to physicians and patients where a patient received fast relief without having to use additional medications or see the physical therapist. PICs was both a part of medicalization in the sense that it was still part of the system and the market, but in some ways it could also cut back on unnecessary and costly exams and treatment.

Doctors did admit that a significant amount of patients chose PICs because the approach to patient care was more intimate albeit less so at a biomedical pace and had the potential to address multiple issues while including the life context of the patients themselves. When explaining why patients sought out homeopathy at the health post, one physician explained how the challenges SUS struggled with influenced patient choices:

> I think it's this quest to balance. Many people, many people today are beginning to be afraid of medicine – of the side effects. The other [reason] is a dissatisfaction with private medicine and the lack of attention of the doctor, of the consultations of five minutes. It's a game that pushes them around right? "This is not me, go to the other specialist, to the other, to the other." That's what we tell the patient here right now that sometimes if you have many doctors, you do not have any. It's no use going to the cardiologist, the urologist, the nephrologist, the gynecologist, that none of them will look at you as a whole. Because everyone will see that little piece, and will send you away with a prescription that will not do it.

A key complaint for AM patients was just what the physician expressed as the "game that pushes them around." Patients could find themselves being passed from one specialist to the next like the patient with lower back pain. Acupuncture was a way to interrupt this cycle and offer the treatment at the health post. It made coordinating care and treatment significantly simpler. Balancing what patients wanted and needed, however, was a difficult line to walk. Physicians complained that patients were often drawn to treatments they historically did not have access to. Just as certain traditional home remedies became fashionable to the middle class, allopathic treatments had become something desirable by underserved populations. This "grass is greener on the other side" phenomenon often meant that what people wanted was heavily colored by what had been historically scarce. Those with less formal education were sometimes considered easier patients in this regard as they were more open to multiple treatment modalities. Most physicians agreed that regardless of what patients came in asking for or were open to, the presentation of treatment options was a way to satisfy patient needs and requests and to keep them in the system of care even if this required some negotiation around treatment plans. There seemed to be a general assumption that keeping people "in" the system was for their own good.

SUS physicians complained that often times people just wanted a rapid consult with a prescription at the end. SUS physicians often complained they did not have enough time with or for patients. SUS physicians found themselves trapped in a web of trying to foster patient satisfaction under time pressure and the expectations of patients who wanted treatments that might be medically unnecessary and violate SUS principles of equity or cost effectiveness. Since AM was perceived as not being "quick" whether it fixed anything aside, it was also seen as sometimes incompatible with patient needs and demands although most physicians expressed a

vague openness to it that stemmed from an equally indefinable belief that AM was in fact an effective form of medicine. One healthcare manager explained this internal struggle:

> I know that AM would probably be something in my life I should opt into at some point. I can't bet on this from the public point of view; I have to deal with those needs and solve them with say … antibiotics. The patient will feel happy as long as there is a remission of symptoms. I will avoid rheumatoid fever, which causes costs and causes suffering, so for me allopathy is more efficient at that time. But at some point, I can come to the conclusion that if I had dealt with anthroposophic medicine from the start, I would generate less suffering. I will have less costs because I will not use so many drugs, or I will not bet so much on the pharmaceutical industry. So why haven't I used anthroposophic medicine to this day? Today I have no endorsement for this, do you understand? So we cannot deny or exclude this possibility, but we cannot bet on it at that moment. It's the same dilemma of integrative practices as a whole.

Here integrative medicine falls into the same trap as AM. The burden of proof for efficacy and the chance health care managers have to take that an AM approach stems further more complicated and costly problems from developing is one that many healthcare managers are unwilling to take. Keeping practices complementary and therefore secondary means less risk financially and moves patients through quickly – or so the common logic would have us presume.

Despite the fact that AM remained somewhat isolated from SUS, several SUS physicians were not the least bit surprised that AM attracted a steady stream of patients or that the AM approach to care had considerable therapeutic value. The general rule was that the doctor who pays attention is the doctor who is closer to reality.

> Biomedicine does not give answers to all questions and it ended with the passing … with its technization, this medicalization of life, which ended up leaving aside biopsychosocial aspects, broader aspects, a broader approach, a more holistic approach, let's call it, a more person-centered approach. Biomedicine left that aside. These [PIC] techniques in general, these practices, they will reconstruct this path, because they are practices that will address … will want to know who you are, where you come from, how is your family --- things in dialogue that the doctor or the nurse does not have room for in conversation and the patient wants to say it and knows that it is part of her care. So I think it [opting into PICs] comes from a lack of answers from many complaints that are not, have not been classified, or the therapeutic responses that we have are more ineffective than effective and do more harm than they really do good. So, for example, chronic pain. People will have a number of therapeutic drugs in the arsenal that to date does not have strong scientific evidence and can cause a lot of damage. And the other approaches will look at this differently and perhaps give therapeutic options that do not do so much harm, that may not be so evidence-based as well, but that they take more care that they heal and are not associated with the damage a drug

> long-term can cause. So, I think patient choice comes, there comes a lot from this biomedicine crisis, like this -this search.

There was little question that patients were looking for PICs and to a certain extent because they wanted a different form of care rather than just a different kind of medication, which might have been popularized for a number of reasons revolving around consumerism. Nevertheless, SUS physicians' views of choice often assumed choice was associated with wanting something more "natural" or that there was a prejudice against conventional medicine. Most physicians explained that both in regards to PICs and biomedicine, people were frequently being misled on social media for example about what was "good" or "bad." Most SUS physicians explained that despite their assertions of doctor shopping and ideas that consumerism had popularized PICs in many ways that (unless they were middle class) patients did not show up wanting PICs. They used it because the doctor suggests it and they trust the doctor. Sometimes physicians had to convince patients to use PICs and other times they had to convince patients they really need allopathic medicine and not tea although less often. One physician was careful to point out the differences he saw in how AM patients approach choice, however, and how his SUS patients approached choice:

> Sometimes it is not the patient that chooses; sometimes I urge the patient to do so depending on the situation … if I have a good belief that it will help. And often we use complementary medicine mixed in with normal patient medicine and they neither notice or already have incorporated it. If the patient has pneumonia, I can give an antibiotic; I can give paracetamol. These conventional allopathic medicines I can also give with a little vitamin C together. It already has evidence to be considered allopathy – conventional - but in the form of an orange per day. And I can prescribe a tea of guaco, a tea of something together, everything already enters the package. So, I do not even worry about what is conventional, which is complementary, everything comes together. But sometimes patients are looking for it. They come in and say "no, I want to do acupuncture" because they already did it because they liked it, because they read about it. AM patients are a bit different, because they already come … usually people who already have children who study in anthroposophical school come, as if it were a clan or a group, like that. So a small group but there are some people who practically only consult with anthroposophic doctor and they appear in the health center from time to time when they are in an emergency or some other problem. These consultations are very expensive with anthroposophical doctors and the remedies are bizarrely expensive.

This physician captures a key difference in patients who seek AM care as opposed to patients who seek care solely through SUS. AM patients tend to route all of their care through their AM physician who reads their exams and may accompany them to the hospital or to treatments. Most AM patients used SUS but for exams, emergencies and for some cancer treatments although cancer treatments were done in conjunction with AM care. The perceived "outsider" nature of AM is captured here with users characterized as some "clan or group" funneled into care by means of participating in Waldorf education. While this is an important conduit for word of mouth about AM care, this is far from the reason that patients seek AM as will be addressed in the following chapter.

5.8 CONCLUSION

SUS in many ways shares the same goals as AM beyond simply alleviating suffering and eliminating disease. After all, AM physicians were trained in similar social and medical contexts. While there was more diversity in explaining patient care and the challenges and success of the public health system, SUS physicians all expressed a firm belief in public health for the public good. SUS was meant to represent a milestone in the development of the country and those that participated in this system seemed to see themselves as much a part of that legacy as they did their own municipal health posts. The idea of family medicine in SUS as being the medicine of the people and the doctors of the people highlighted important exceptions to whom those people were who used the system and shaped the system, however. While it was clear from interviewing patients and physicians that the bond that physicians and SUS aspired to was not always possible or done, it was clear that those aspirations were something intrinsic to the values and history of

SUS itself*: "The Family health strategy is a strategy that aims to strengthen SUS principles, to work more at the local level, with the community, to have a family physician in the community, community health agents that go to people, who make this strong bond with the community."*

The decentralization and "municipalization" of SUS was designed to make the system flexible and permeable to the demands and needs of patient population. In areas where the system was not overloaded and their was considerable political will and mobilization, the system had the potential to achieve impressive milestones. But there were numerous challenges to SUS from financial pressures and medicalization, to overwhelming need unmatched by resources. There was never one culprit or one area to be fixed (Gragnolati, et al. 2013). Instead, challenges came from government priorities, private insurance industries and sometimes as this physician explained, from patients themselves:

> It is often the fault of the patient's disregard for health. Sometimes it is the fault of the system that does not respond to all the needs or all the demands of the people. There is a need for health education but that demands a lot of time, right? And the ideal is that this is a system [SUS] that responds better to people's needs, right? So we cannot be responsible for so many people in order to avoid having so much overload. [We should] have the complete teams, with doctors, nurses, with health agents right? It is: a system of control of these expenses, of those situations that duplicate and cause an excessive expense to the system. It's also social control. One of the legs of SUS is the client -the patient, society - and that is flawed in Brazil. So we know that in all the places where the residents' associations are active, where you have the active health commission, things are much better. You can do a job education but it is also promotion of people's health -not only on the side where you have to take the medicine right? But we have to take care of garbage, water, social life, surroundings, beauty, for example. And among these other things comes integrative practices in the sense that you show people that there are other things.

PICs in this wider context of Brazilian healthcare reform and the evolution of SUS and SUS physicians' approach to patient care were a means of giving physicians other practices to appeal to patients even if doctors were more or less optimistic and assertive about using them. Here this physician goes as far as to assert SUS was a system of social control. Through PICs, doctors could offer choice and extend the reach and attractiveness of this system of social control.

Some physicians seemed to relegate PICS to a last resort effort if biomedical treatments

did not work, others wanted to use them to cut back on the dependency on biomedical medications and the pharmaceutical industry and others saw PICs as an opportunity to recover certain aspects of patient care that were missing in a system that was dominated by technology, cost efficiency and overload. Others cast PICs as the logical step in the evolution of a medicine by and for the people. Brazil was always referred to as a country with a strong popular culture, a syncretism of people and traditions that ranged from Africa to Portugal and everywhere else in between. Having PICs in the national healthcare system brought together the diverse medical traditions of Brazil, a boundary object to unify and celebrate the diversity of the Brazilian nation. This diversity was something that people referenced as a reason for Brazil's openness to difference and syncretism. Just as attention to the variety of illness and patient ages, genders, sexual orientations and religions was something SUS physicians prided themselves on attempting to connect to and respect, PICs and the diversity of the population was something that family health practitioners considered part of their practice:

> In family medicine, we like to be close to the population. We are proud to be close to the population. We also develop pride in this. We like to have contacts, to link with cultural aspects, to absorb the different cultures , to be able to use and expand ours because again, in family medicine we are concerned with working in community, in primary care. We are worried about what the person brings to us. Sometimes a single answer based only on strict medical training does not work. Because of this strong organization, history of the SUS and the history of SUS within primary care and with community practices and popular practices, it has community and popular practices that greatly influenced the formation of SUS and until today you have, for example, in the Ministry of Health sector that works with popular health education. Because of this cultural force, this cultural force influences politically and influences the clinical practice of physicians, with all that influence we had to have some political mobilization. Management is nothing more than the organization of the various political demands that come; we organize a service that is based on laws and norms, which are influenced by the political and cultural composition of a people, so I think that was it, I think Brazil absorbed this [PICs] from our culture.

The physician quoted here had spent decades working in public health. He had trekked by boat to isolated communities to provide vaccinations and worked with some of the most isolated and poor communities in the country. His descriptions of the days before SUS sounded like a romanticized version of "Heart of Darkness" – the fearless comrades undertaking the perilous

journey into the wild in order to bring care and alleviate suffering. He described his companions as a group of idealists who were doing the work of PSF teams (*Programa de Saúde da Família)* long before health agents were a formal part of the health system. PICs were a continuation of this idealism. It was a way to bring the medicine of the people to the people, to amplify care and pay homage to Brazil's diversity through a system that formalized it in practice. He described this process as:

> So there are projects of this type in Brazil for a long time, a lot of people, a lot of people have already given blood for this and willingly, right? You have to want it too. There is no way to say why this desire is born in people and not in other. I already went into medicine with this idea, I do not even know why. And I got to know people throughout my search who were influencing me on this political side of thinking that medicine has to be at the service of people.

It is clear from speaking to SUS physicians that they have a vision of SUS and their role within it that is deeply rooted in the ideals of Sanitary Reform and the milestone that a public healthcare network for all it was supposed to represent. For many, this carried on into advocacy for PICs themselves. While they acknowledged the challenges facing the system, there was an indomitable faith that the idealists would carry on, that the people would remain mobilized and the system of the people would endure and evolve. There are notable inconsistencies in the view of PICs and assumptions about AM that remain unaddressed and unchallenged, however, with little to no input or participation from AM in the area on the decision-making level. Patients, while they recognized and sometimes echoed the idealism that underpinned the creation of SUS, their perspectives as users offered a distinct perspective from the picture their physicians had painted.

6.0 CHAPTER 4: ANTHROPOSOPHIC MEDICINE AND THE PRODUCTION OF PERSONHOOD

6.1 AN INTRODUCTION TO ANTHROPOSOPHIC MEDICINE

Anthroposophic medicine (AM) is an integrated multimodal approach to medical care that utilizes both conventional biomedicine and treatments based on a holistic understanding of the human being and its place in nature. It is practiced in over 80 countries worldwide in settings that range from large hospitals to small private practices by licensed physicians as well nurses, and therapists offering treatments that include all acute and chronic diseases. AM treatment can include art therapy, eurythmy (form of movement therapy), rhythmic massage, music therapy, and biographical counseling. There are 24 anthroposophic medical institutions in Germany, Switzerland, Italy and the Netherlands and the U.S. (Kienle, et al. 2013). Despite its wide reach and diverse treatments, AM remains less widely known outside of its birthplace in Central Europe, and concentrations in South America (Kienle, et al. 2013; Kienle, et al. 2016).

AM came out of the *Anthroposophy* (Greek: *anthropos* meaning man, and *sophia* meaning wisdom), a philosophy established by Dr. Rudolf Steiner (1861-1925). A student of mathematics, the empirical sciences and philosophy, Steiner developed Anthroposophy in the

early 1900s inspired by his study of the scientific works of Goethe (Hamre, et al. 2014; Lindenberg 2012; Steiner 1928; Steiner 1886). Anthroposophy arose out of three traditions: the empirical traditions of modern science (17th century onward), the cognitive tradition of philosophy (as established by Aristotle and Plato, through the German idealism of Hegel, Fichte, Chelling, Schiller and Goethe), and the esoteric tradition of Christian spirituality (Büssing, et al. 2015; Kienle, et al. 2013). Steiner wanted to develop a rational holism that could extend materialism and move beyond it (Heusser, et al. 2012). Anthroposophy was posed as an expansion or sequential step in Western thought and science for Steiner, who rejected the tradition of Kantian reductionism and materialism and argued that the human cognitive capacity could be expanded to investigate phenomenon beyond the material sphere (Kant 1918; Steiner 1981). "*Anthroposophy represents a view of man and nature that is spiritual and that also claims to be profoundly scientific* " (Hamre, et al. 2014).

According to Steiner's formulation, the human being is a multilevel organism with diverse subsystems and interrelations among these subsystems (or forces) adding what some might call a "spiritual" dimension to the natural science view of the human being. His extended view of the human being and nature posits human beings as a physical body with an inner life, body, soul (mind and emotions) and spiritual ego (self awareness)(Arman, et al. 2011). This view of the person and its place in the world is applied to practical fields such as agriculture (biodynamics), eurthemy, education (Waldorf schools), renewal in various art forms including dramatic art, painting, sculpture, and architecture, and efforts to shape social life (three-fold social order), and Anthroposophic Medicine (Kienle, et al. 2013).

Anthroposophical Medicine came out of the combined efforts of Steiner and Dr. Ita Wegman who worked with a group of physicians to apply the principles of anthroposophy to the

defining what constituted the human being as well as health and disease. It was designed to extend biomedicine rather than act as an alternative to it (Arman, et al. 2011; Heinz, et al. 2012). In the application of anthroposophy to medicine, illness indicates abnormal interactions among the different levels of the human being and since all of the levels are interconnected, illness is also considered a reflection of all of the aspects of the human being(Arman, et al. 2011). These levels are often referred to as *The Four Constituent Elements of Man* and the *Three-fold Man*. *The Four Constituent Elements of Man*, also known as the "*Four-level Concept of Formative Forces*," is a model of the human being as a 1) physical being that is also made up of 2) formative growth forces (etheric body), 3) the anime/ soul (astral body) often associated with the sensory, motor, nervous and circulatory system and emotional life and 4) the spirit forces (ego body), which both interacts with and supports the other three forces or bodies and the expression of the individual mind.

In its most basic interpretation, *Three-fold man* or *The Threefold Model of the Human Constitution* is the division or location of two polarities: the nerve sense system (predominately in the head), and the metabolic system (predominately in the limbs). These two polarities are mediated by the rhythmic system (predominately in the respiratory and circulatory organs). These three systems exist throughout the human being but are predominate in their respective regions. All three regions are permeated by the 4 constituent elements of "man" (Kienle, et al. 2013).

According to the AM view of the human being, pathology can be thought of as deviations or disruptions in the normal function and in relationships of the systems and forces referenced above. Included in this view of the human being is a significant emphasis on the dignity and autonomy of individual beings and their agency. Anthroposophic healthcare practice is deeply

rooted in a commitment to respecting individual autonomy and helping individuals help themselves though self-healing, the creation of coherent autonomic regulation and emotional and spirit self-regulation. Therapeutic goals are aimed at strengthening inner resilience and the capacity of the formative forces. This has to be done on an individual basis rather than a standardized program, which is why AM care is considered patient centered. Here patient centered is characterized by:

> Knowing the patient as a person, by exploring both the disease and the illness experience, and by ensuring that patient values and needs guide all clinical decisions. This includes sharing information and deliberation, tailored to the patient's concerns, beliefs, expectations, and literacy; allowing the patient to question medical assumptions and understandings of facts; promoting a listening, trustful, empathetic, and healing relationship; and involving family and friends (Kienel et. al 2013: 489).

AM physicians pay special attention to the resilience of their patients, the degrees to which they are coping, their ability to set boundaries and manage positive and negative life events, biographic issues and patterns and social relationships. Physicians also examine the values, interests, personality traits and hobbies of their patients (Kienle, et al. 2016). For these reasons, treatments are not only aimed at alleviating suffering and symptoms but also at restoring health by promoting the strength of the whole constitution of the patient through multiple approaches. In order to achieve this, AM practitioners focus on all dimensions of health and direct healthcare plans to address the physical, emotional, mental, spiritual or social needs of their patients (Kienle, et al. 2013; Medicine 2009). Approaches to care also depend on whether the doctor is the primary doctor treating the patient. AM doctors may be treating an oncology patient in a supporting role while the oncologist occupies the primary role for example. AM doctors will also consider, whether the patient has made certain requests, how willing the patient is to undergo treatment or whether the patient needs curative vs. palliative care (Kienle, et al. 2016). Treatment for chronic illness may also vary from acute illness since the emphasis will be

on "*counteracting constitutional vulnerability, stimulate salutogenetic self-healing capacities, and strengthen patient autonomy*" (Hamre, et al. 2010).

6.2 TYPES OF AM CARE

In order to become an anthroposophic *physician*, one must be a licensed biomedical physician and complete additional training that is both defined and regulated on national and international levels to standardize curriculum and expectations. This usually includes a year or more of training in an anthroposophic curriculum and 2 years of medical practice under the guidance of a mentor. *The International Federation of Anthroposophical Medical Organizations* represents the political and legal affairs of Anthroposophic practitioners, and the guidelines for ethical and professional standards and practice. *The International Postgraduate Medical Training (IPMT)* in Anthroposophic medicine for example, is a certification process through a series of yearly training sessions that last a week at a time over the course of three years. This allows registered physicians to earn the certification even if they do not have an anthroposophic physician or training program locally and to ensure that training certification, continuous medical education etc. are all consistent.

AM is strongly organized internationally with full curriculum training available in Argentina, Austria, Brazil, Chile, Cuba, Denmark, Estonia, Finland, France, Georgia, Germany, Hungry, India, Israel, Italy, Japan, Latvia, The Netherlands, New Zealand, Norway, Peru, The Philippines, Poland, Romania, Russia, Spain, Switzerland, Taiwan, Ukraine, the United Kingdom, and the United States (Kienle, et al. 2013; Koster, et al. 2014). Brazil for examples

offers training in several different cities such as São Paulo, Juiz de Fora and Florianópolis although course frequency is dependent on enrollment.

AM medical training is highly focused on medical knowledge (remedies etc.) as well as teaching patient engagement. One of AM's key tenets is its commitment to patient-centered care. AM's focuses on paying "*attention to antropos, the human being. In practice it means a professional orientation to the individual, an equal relationship between patient and healthcare provider and much time and attention for the patient, or in other words, patient centered care*" (Koster, et al. 2014). This requires providers to be skilled in qualified listening and empathy. In biomedicine, it is well documented that medical students experience profound shifts in the way they engage patients as they are encouraged to master technical skills rather than interpersonal ones such as empathy (Scheffer, et al. 2012; Scheffer, et al. 2013). This is in part due to the frequency that doctors encounter suffering and loss while needing to maintain composure and impartiality.

Brüssing et al. (2015) suggest that the relational aspects of spirituality in AM enable providers to cope with intense stress and avoid "cool down reactions" or withdrawal of engagement with patients. Brüssing et al. (2015) also suggests that this enables practitioners to be more accessible and engaging where oftentimes biomedical practitioners learn to withdraw in order to self-protect and maintain professional distance (Büssing, et al. 2015). AM addresses the so called "hidden curriculum" that can arise in biomedical schools by modeling a different approach and offering active student learning based courses in clinical education. While these programs have not been shown to have different outcomes after the patient is discharged, it has demonstrated that active student learning fosters better collaboration between health professionals and better listening skills and empathy. The patients of students in these programs

also rated their student physicians higher. This may also stem from the ability of these students to dedicate more time to each patient since they also had lower patients loads than their non-AM counterparts (Scheffer, et al. 2013).

While mostly found in Family Medicine, AM treatment is offered in multiple sectors and specialties practiced by a variety of specialists. Even when a physician creates a treatment plan with their patients, other practitioners often become involved in that treatment protocol. AM care involves collaborations between nurses, therapists and counselors (Ben-Arye, et al. 2013; Koster, et al. 2014). Nursing care, art therapy, music therapy, Eurythmy therapy, external applications and rhythmic massage (and more) can all be part of a patient's treatment. Art therapy, for example, can be provided as an individual or group therapy that incorporates sculpture, therapeutic drawing and painting, music therapy, singing therapy and anthroposophic speech therapy depending on the needs of the patient(s). Both the art therapist and physician carefully decide these needs.

Certain types of art therapy can be helpful as well as harmful depending on the patient and their health. Sculpture for example, is considered a practice that draws the ego forces very firmly into the body, which according to AM epistemology, can be harmful to pregnant women whose ego or spirit body must be more loosely integrated with the physical body in order to accommodate another developing being. During medical training in Brazil, the art therapist leading our sculpture session made it clear that anyone who was pregnant or was feeling devitalized by the process should not participate in order to protect his or her health. Instances like this one, illustrate the seriousness afforded to additional therapies and the degree of training practitioners are expected to complete in order to make assessments about individual patient needs. In order to become an anthroposophic art therapist, for example, one must complete four

years of college training and two years of professional experience under a mentor (Kienle, et al. 2013).

Eurethmy is another important treatment tool that AM practitioners use to develop patient's capacities and/or address patient pathologies. It is often thought of as a kind of dance but is a type of movement therapy often aimed at improving breathing and posture and strengthening overall physical vitality. In Greek, it translates as "harmonious rhythm" and uses movements that correspond to vowels, consonants, music and music intervals and expression (antipathy or sympathy for example) in either small group or individual sessions. During these sessions, patients may be guided through selected movements with the hands, or feet or the whole body that correspond to the patient's illness, constitution or how the patient carries themselves. Qualification to become a curative eurythmy therapist (not a performer) is 5.5 years of training in an internationally standardized curriculum (Kienle, et al. 2013).

Two other common AM treatments are Rhythmic Massage and Psychotherapy. Rhythmic massage was developed by the co-founder of Anthroposophic Medicine, Dr. Ita Weman. Using traditional massage techniques, massage therapists included complex movement patterns, rhythmical movements, plant oils, and loosening techniques. Massage therapists are physiotherapists with 1.5-3 years of additional training according to an internationally standardized curriculum (Kienle, et al. 2013).

Psychotherapy and Counseling take several avenues in anthroposophic care and include biographical – existential counseling, nutritional counseling, and counseling for social, mental and spiritual issues since all of these aspects are central to the anthroposophic view of the human being. In addition to the three psychological counselors at The Clinic who had trainings in somatic experience and biographic counseling, anthroposophic psychiatry was also represented

in Florianópolis using both conventional and anthroposophic treatment methods for patients (Kienle, et al. 2013).

6.3 PREVIOUS RESEARCH ON AM

As Anthroposophy has gained more international visibility over the last decade, so have questions around its efficacy, effectiveness and safety. Early anthroposophic initiatives in the 1920s and 30s were accompanied by intense research that was interrupted in the lead up to and culmination of the Second World War when Hitler denounced Steiner and the Anthroposophic Society and their associations and publications were banned (Werner 1999). Research efforts reemerged in the 1970s and 80s contending with the ever-popular golden standard of measurement: the randomized controlled trial. This proved problematic for AM for several reasons. The highly individualized nature of treatment and in particularly non-pharmaceutical treatments are difficult to assess with randomized controlled trails – an issue many integrative healthcare modalities encounter (Kienle, et al. 2013). That being said, AM has been increasingly visible in a variety of studies internationally.

A comprehensive review of the literature on efficacy and effectiveness of AM treatments in 2013, showed that AM had been examined in 265 studies, 38 of which were randomized controlled trials, 36 prospective studies, 9 retrospective nonrandomized controlled studies and 142 observational studies. Of these 265 studies, 253 showed positive outcomes, 12 found no benefit, and 1 showed a negative trend compared with purely biomedical counterparts. They also showed that AM treatment groups had lower use of antibiotics and antipyretics, higher rates of patient satisfaction, fewer adverse reactions and quicker recoveries even after adjusting for

country, age, gender and baseline severity. Because AM treatments often include fewer referrals, fewer hospital days/admissions, and lower drug costs, it may also be more cost effective. Heinz et al. has shown that AM treatment of acute ailments may require longer hospital stays, however, which has raised concerns over access if insurance programs do not cover longer hospitals stays (Heinz, et al. 2012). (In Brazil, cost burden is usually distributed more fully to patients since AM remedies are not reimbursable and biomedical medications are).

The above studies were aimed at assessing a variety of AM treatments within a variety of diseases with 38 studies designed to examine AM care as a whole, 10 at non-pharmacological therapies, 84 to examine other AM treatment strategies, and 133 on mistletoe treatments (Kienle, et al. 2013). The largest clinical outcome study on AM to date is the *Anthroposophic Medicine Outcomes Study (AMOS),* a 4 year prospective study with 151 physicians and 1631 patients conducted in Germany between 1998-2005, which resulted in 21 peer reviewed publications on patient outcomes including symptoms, cost, and satisfaction (Hamre, et al. 2014). The AMOS set the stage for later studies that indicate AM patients show higher rates of satisfaction and quality of life than patients in conventional treatments (Arman, et al. 2011; Carlsson, et al. 2006; Hamre, et al. 2007; Koster, et al. 2014).

The majority of the research on AM is not published in English (or Portuguese), which directly contributes to its low level of recognition and acceptance outside of regions where it is more robustly established. Research published in English (and outside of Europe) has become particularly visible only within the last ten years, most of which within the last four. This is in part due to the push by European researchers to make their scholarship more accessible by publishing in English and in clinical and public health journals with wider distribution, and by the growing visibility of evaluation studies and an anthroposophic cancer remedy *Viscum Album*

or mistletoe, which is and has been in several studies in the U.S. Mistletoe therapy has been shown to have multiple effects including the enhancing the cytotoxicity of anticancer drugs, stimulating the immune system including activation of macrophages and T-cells among others, and improving factors associated with quality of life such as: sleep, appetite, reduced fatigue, exhaustion, nausea and depression (Büssing 2000; Kienle and Kiene 2010; Kienle, et al. 2013; Siegle, et al. 2001; Valentiner, et al. 2002). In 15 randomized trails and 9 non-randomized trails, mistletoe therapy also has been shown to improve quality of life and health outcomes during and after chemotherapy, radiotherapy and surgery compared to patients undergoing purely biomedical treatments (Ben-Arye, et al. 2013; Michaux 2017).

Cancer therapies have become largely associated with AM because itss approach to patient care addresses some of the larger concerns and hurdles conventional biomedicine encounters when treating chronic conditions. Chronic illnesses necessitate a heightened degree of self-management by patients that require them to be attentive to their own treatments and symptoms as well as responsible for problem solving, lifestyle changes, and decision-making. Within AM, problem solving and decision making are by nature more collaborative since doctors treat patients as the experts on their social, psychosocial and existential lives (or a patient's own *lifeworld*). The crisis facing evidenced-based medicine has been an asymmetrical research agenda that has focused on experimental evidence and developing technical skills rather than patients values, when doctors are often judged by patients on their interpersonal skills (Kienle, et al. 2016). Consequently many patients have turned to "Complementary and Alternative Treatments" to augment their care and researchers have turned to randomized controls trials of CAM to assess safety, effectiveness and efficacy such as the work on mistletoe.

6.4 LIMITATIONS IN IMPLEMENTATION

Because of its growing recognition as a health resource for a variety of maladies and concerns, AM doctors have been more and more successful integrating into national healthcare systems. Integrative efforts in postgraduate medical training in AM tend to be successful in hospitals with well-structured department features, and systematic training whereas larger hospitals make this integration more difficult (Heusser, et al. 2014). In places like Israel or Brazil, this integration is not always even or entirely possible since medical plans, lack of knowledge about AM, and accessibility to AM physicians are all issues (Ben-Arye, et al. 2013).

Some of the more difficult aspects of integrating AM arise due to its medications. AM has been used for nearly 100 years in Europe with an evident safety record. Even for "high-risk" AM treatments (injections), the risk of side effects is 0.000036%. *Viscum Album* for example is used as part of treatments for 50-70% of the oncology patients in Germany and Switzerland (Michaux 2017). Products like mistletoe are used and manufactured according to prescribed guidelines. Compared to biomedical drugs, they are often cheaper *if* biomedical drugs are not subsided or covered by insurance (Michaux 2017). While some AM products are over the counter, others require prescriptions. This varies country by country. In Brazil for example, you do not need to be an AM certified physician to prescribe AM medications. Some AM medications are available over the counter in general pharmacies. Others have to be obtained at specialized pharmacies, of which Florianópolis has one. Coverage of remedies by governmental or insurance agencies largely relies on proof of efficacy. Efficacy studies on AM run into several obstacles ranging from the individualization of treatments (difficult to create control groups), to difficulty funding scientific research on non-conventional medicinal products due to their low

profit margins. Some have also argued that AM products have subtler effects making it difficult to achieve statistically significant results (Hamre, et al. 2010; Michaux 2017).

Gaining access to AM care is complicated by varied access to AM medications, which is difficult to integrate into existing pharmaceutical laws, registration, marketing and distribution regulations. While AM does use homeopathic products, many of its preparations do not meet homeopathic or traditional herbal product criteria. Additionally AM medications operate and are manufactured under different principles: "*The rationale for AMP therapy is based on typological correspondences between pathophysiological processes in man and formative forces working in minerals, plants, and animals while the simile principle of homeopathy is based on symptom correspondences*" (Hamre, et al. 2014). Their substances, dilution levels and manufacturing processes often exclude them from being considered homeopathic (Hamre, et al. 2014). Certain AM manufacturing processes for example require people rather than machines to process them and for substances to be harvested during specific times of the year. This makes them more difficult to mass produce, less vulnerable to being appropriated by pharmaceutical companies, more expensive if unsubsidized by health insurance plans and also more difficult to prescribe.

There is an *Anthroposophical Pharmaceutical Codex* for good manufacturing practices of AM remedies, which are produced by several companies such as: *Weleda*, *Wala*, and *Abnoba Heilmittel* (Michaux 2017). *Weleda,* for example, is the most popular in Brazil. Even though some of the AM medications are manufactured in Brazil, their ingredients are sourced from abroad (Europe) making them particularly expensive. SUS does not reimburse for these products in Florianópolis for example even though SUS physicians are still allowed to prescribe them. Brazil as well as Switzerland and New Zealand do recognize the *Anthroposophic Pharmaceutical Codex*.

Many physicians and patients cited access to AM medications as the primary barrier to participating in AM care. It may have also contributed to the perceptions (often from SUS providers) that AM medicine was for the elite or wealthy. AM practitioners were well aware of this barrier and were equally frustrated by it. As one of the physician's at The Clinic put it:

> The thing that is difficult about anthroposophic medicine in SUS is the price of medications. Anthroposophic medications are still expensive, even for patients from a higher socioeconomic level. They always complain that the anthroposophic formulas [medications] are never less then R$70 or R$80 and many times you need to augment one or two of the formulas. So for the needy population, it becomes a little more difficult to access. This is one of the biggest complaints that we [doctors] have in medical conferences. We are always in a debate about how to bring anthroposophy, how to avoid treating only the elite and to go to the lower classes. It is difficult to justify the price of medication.

This AM physician was well aware of the cost burden AM care could place on patients. She and the other Clinic physicians I interviewed either mentioned they took this into account when they could in terms what they recommended and charged for or I observed this directly while at The Clinic.

It should be noted that AM initiatives in low-income areas like Monte Azul in São Paulo, do make efforts to provide care to Brazilians from all walks of life and The Clinic was frequented by patients from different socioeconomic statuses although slightly skewed to middle class Brazilians. Still, the dynamic between European companies selling products to Brazilians who could not always afford them raised debates about purity, quality, ownership, authenticity and nationhood. While some argued the prices of medications were high because laboratories like Weleda adhered to strict quality control in all ingredients and manufacturing (that some suggested would not be maintained in Brazil), others saw it as an exercise of power over the Brazilian AM community – a kind of post-post colonialism.

Some AM doctors saw the schism between medication price and affordability in Brazil as an opportunity to also make the case that in order to make AM "Brazilian," doctors should

also learn how to use local varieties of medicinal plants particularly since Brazil has an impressive biodiversity that Europe does not have at its disposal. One doctor in particular saw the lack of use of local varieties or value of traditional medical knowledge from African and indigenous populations as a vestige of Brazil's colonialist and imperialist past and a barrier to making anthroposophy Brazil's own:

> I would say, there exists a "monopoly" of the laboratory Weleda, which is something that is not "real" … as if it were the only option for the anthroposophic physician to prescribe. And it is a laboratory that works a lot with imported ingredients, European ingredients, which, because they are imported, become very expensive. I always fought the lack of training and knowledge of the native resources [in local varieties of plants] of doctors, hence my interest in ethnobotany as well. Local plants would make the prescription ten times cheaper, which is what I do. I prescribe Weleda very little. Not to speak poorly of Weleda; I am saying it is a commercial problem there with the imports and taxes and everything else that makes Weleda medication less accessible for the majority of people. And Weleda's own policy too, I might say, I do not know why, internally they do not ... they are that way. The thing is, the laboratory [Weleda] is not from here; it is from there, and the guidelines are given there. It seems that people there do not really know what the reality is like here. Here it is not the same economic standard. So the solution I have seen, what I do, is to use other means to make prescription much cheaper and very accessible to anyone. But not all anthroposophic doctors are aware of this; they continue to prescribe [like they are] there [in Europe] and I already see situations in which a colleague prescribes and the patient picks up the prescription, puts it in his pocket, leaves, but does not buy it because he does not have the money for it. And I cannot do this; I have to ask: "Can you afford it? Is it within reach?" If he says "no," it is my duty, not his, to resolve it. He will not know what the options are. I have to know: well then there is this option here that is cheaper, this replaces that. It is the responsibility of the doctor, not the patient. That's why I am sometimes invited to conferences, training courses to talk about Brazilian plants.

For most other AM doctors, the divide was not quite so stark and they objected to the idea that AM was not already Brazilian. They often noted Brazil's frequent use of biographical counseling (and Europe's underutilization of it in comparison) as evidence that Brazil had already made AM its own. They also pointed out that AM physicians who worked in SUS in particular often partnered with pharmacies to make medications more accessible to low income patients or sought homeopathic / herbal alternatives that often *did* use local plant varieties.

Private AM doctors often referred patients who were interested in AM but could not pay for private care to AM colleagues on the island who worked in SUS health posts although patients were generally limited to being able to use their neighborhood posts. Several doctors

also used sliding scales for appointment fees, waved appointment fees if the medications were particularly expensive that visit, or did exchanges with patients. One AM physician accepted artwork from a patient who was an artist since they were unable to pay her. Many physicians (and their patients) reported using multiple means to make medications and care more accessible. During a bout of food poisoning for example, I was prescribed two teas made from native plants most people (myself included) had in their own backyards rather than anthroposophic or allopathic medications. The treatment was both effective and free.

Many physicians (anthroposophic and biomedical alike) identified the issue of medication as being one that not only limited patients from accessing AM, but also limited the ability of AM physicians to practice AM contributing to this idea that AM was for the upper classes. AM physicians described the issue of medication as a "bottle neck" where the interest of patients and physicians in engaging with AM was thinned by too few pharmacies selling the medication and too few patients able to buy it. While Brazil has a tremendous uptake in the number of physicians becoming certified in AM (that rivals Europe), one AM physician argued that only half of them would go on to practice AM particularly if they worked in SUS and were limited by time and what patients could be reimbursed for. This was one of the explanations for why Brazil had 14,000 homeopaths (who do get reimbursed by SUS and/or have less expensive medications) but ~500 AM physicians (her numbers) that was repeated from multiple physicians and multiple healthcare coordinators. While AM practitioners have a record of finding ways to incorporate their AM practice into their SUS health posts, regional health managers can make or break that success. Several practitioners in Minas Gerais for example, attended in SUS with the longer appointment time characteristic of AM consults that was only made possible by healthcare managers who signed off on the extended appointment times.

6.5 INTEGRATION INTO SUS

Despite the fact that Brazil has a national integrative healthcare policy (PNPIC) that includes AM, integration is varied and in Florianópolis, AM is nearly invisible in SUS although still present due to several doctors who practice within the system. Integration is challenging for several reasons beyond medication cost and access. Most AM physicians, who worked exclusively in private practice, cited little to no relationship with their SUS colleagues with a few exceptions. Since AM often attracts oncology patients for mistletoe treatment, several AM physicians worked alongside SUS providers with mixed success in balanced cooperation. Some SUS physicians were open to the partnership while others were concerned about any non-conventional treatment and potential complications that could arise from them. Some SUS oncologists told some patients they would not treat them if they also engaged in AM treatment for example. Partnerships or collaborative care were often complicated simply by practical limitations, such as time. One AM physician explained that while he tried to work with his patient's oncologist and stay up to date with the treatment, the SUS physician often did not respond or update him because the SUS physician had a large caseload and little time to collaborate.

Other barriers to integration stemmed from the interlocking layers of medical bureaucracy -- all with different priorities. While the PNPIC is a national policy, there are also state and municipal levels of healthcare governance that are linked but do not always follow one another or have the resources to do so. AM is recognized by the PNPIC but it is not considered a separate medical specialty. Some AM physicians are in favor of going through the process of making it a specialty while others fear that the process would create a dilution or cooption of the approach – a concern shared by some homeopaths that were reticent to offer the 8 week courses

that train health post doctors to practice the integrative approaches (PICS) like acupuncture, since homeopaths have a 3 year long training, exam and certification process.

While most physicians acknowledged the potential the PNPIC had to open doors to integrative health practices, many cited the bureaucratic and medical culture barriers to implementation. Not everyone shared an enthusiasm for integrative treatments or AM particularly when AM physicians wanted to see fewer patients for longer periods of time. Several SUS physicians also saw AM as only for the elite "or bored middle-aged women" who wanted a captive audience to emote to. The PNPIC did not erase these attitudes by any means. On the part of many integrative health providers, some shared concerns that their practices would be coopted and whitewashed or that traditional treatments accessible to and used by lower socio-economic statuses would be coopted and turned into "boutique medicine." There was hope and enthusiastism on both sides, however, that the PNPIC could make medical care more accessible and more effective for all Brazilian citizens.

While some saw the PNPIC as a political move by the Workers Party government to garner favor, most credited the inclusion of AM in the law as a move by AM physicians and patients within the municipal health governance. (One physician had a patient who was a member of the Brazilian congress for example.) Rather than a mandate to make AM accessible, the PNPIC was an opportunity for integrative healthcare providers to gain a foothold in SUS clinical space but only if the regional health managers provided the framework for it and AM physicians advocated for it. This foothold had to be earned with many extra hours of free labor, fortitude and persistence. In places where AM physicians had strong links with the medical infrastructure and cohesive group movement, like Juiz de Fora or Belo Horizonte, AM was integrated. There was energy on both sides of the line to further integrative medical forms into

SUS in Florianópolis but these efforts did not always coincide. Several AM physicians in Florianópolis explained that earlier in their careers they had been heavily involved in pushing for AM's inclusion but with age and mounting frustration of implementation and evaluation hurdles, they had become less involved. One of these physicians explained:

> [In order to practice AM at the health post] I needed to diminish the consult time [required by SUS doctors] but diminishing the time does not diminish the number of consults [that need to be done at the post] and adds to the consult time. I worked with another doctor. If she attends 12 patients and I attend 4 … that's complicated. Now it would be better if everyone at the health post was made aware of/understood the AM approach. In Florianópolis, I asked for this "sensibilization" to be introduced, which is done by educators who donate their time. These people are … is the Commission on Integrative Health Practices. Some health posts have already been sensitized [to alternative medicine approaches] but others have not been because it seems that they [the commission] want to conclude a stage … I don't know. I already made the request. I have done it two times … and if I am not connected by now … so I let it go. I won't chase after it.

The commission this physician referenced was comprised of physicians who were specialists in several different forms of integrative medicine (like acupuncture) and were heavily engaged in bringing trainings and a greater understanding of PICs to multiple municipalities within the area. They were both enthusiastic and helpful, facilitating my contact with SUS physicians in the region and let me attend several of their meetings. When asked about why AM was not represented at the table or within the regional healthcare system, most attributed to it to either a lack of interest on the part of AM practitioners to integrate or an incompatibility between SUS's needs and resources and an AM approach to care (particularly extended consultation times). They were unaware of the requests made by the physician cited above, quite possibly since the request may have been lost or put to someone who had since left.

Despite the fact that some SUS managers and physicians saw AM as something that would inevitably have to remain outside of the system, it has been fully integrated in places like Belo Hortizonte where the AM approach has been able to align with the values of Sanitary Reform. Many SUS physicians (particularly longstanding health post doctors) cited similar

values or intentions as anthroposophic doctors but within a more limited framework (see chapter 3) and often with less definitional clarity. Patient centered care was used ubiquitously but had a significantly less uniform meaning amongst SUS physicians and administrators. As one AM physician in SUS put it:

> It is like this: SUS has an intension. They like to have coordination. For example, there is an approach in SUS that is "Family Health" right? That is really … it could be really interesting. So, a consult, if the doctor is willing, he/she starts to get to know the context of that child, for example, how that child lives. And the doctor can refer the health team to that family. This is good. It is a way of connecting with the patient that is very close to anthroposophy. But this is not done much in SUS, very little. We should have a … we should explore this area right? To know the context and to accompany a thing, it needs to be a process … this is what needs to happen.

For anthroposophic physicians, shorter visits with patients meant depriving patients of the opportunity to share their life contexts (assert their personhood) and stripped physicians of the opportunity to get to know the patient's life context, which are key to both diagnosis and treatments. For SUS physicians with a long line of patients to attend to, however, longer appointment times and less consults is a hard sell.

6.6 THE ANTHROPSOPHIC APPROACH TO PATIENT CARE

When Anthroposophic physicians explained how they came to work in anthroposophy, they nearly always mentioned their desire to expand upon the conventional approach to medicine. Most physicians found their way to AM during their medical training through study groups, friends, lectures, and happenstance encounters that left lasting impressions. Physicians repeatedly referenced feeling that their patients had unmet needs that conventional biomedicine was not able to wholly fulfill on its own, largely in part because of the way it approached and

framed the human being, health and disease. One physician who found her way to AM by attending the wrong lecture hall in medical school one afternoon explained what captivated her about the lecturer's (Otto Wolf) presentation when he asked the students to define a human being for him:

> What conventional medicine has done, it uses antipyretics, antiallergics, and antibiotics ... What are analgesics? Anti everything! And these days there are more "antis" than before. We have many immune suppressants. We have many anti allergy [medications] now but in that time, when he asked that question – we also had all of these "antis." Everything is against … against, against! But ultimately what is the purpose of the human being? What is it to be human? It was this [question] that touched my soul! This! But I had already heard this before but I had not really heard it truthfully. It was a memory that sprouted and so it was very strong. I was in my fourth year in medical school. It was then I thought I am going to do something in this area.

Many doctors began as family medicine or community health physicians with the intention of being general internists and family doctors. Almost all of them cited a belief that medicine had lost focus and was concentrated on what was urgent but not what was most important. Many were frustrated when patients had to remain on medication for long periods of time or were chronically ill patients who did not improve and remained dependent on their doctors. All of the participating AM physicians reported looking for something beyond the tools that they had learned in medical school in order to help their patients. They were seeking something beyond the material conception of the human being – an investigation that was important for them as professionals as well as individuals. One physician explained his attraction to AM saying:

> I started in anthroposophy because I found the answers I was looking for in this system of understanding the human being. Because the other systems were systems of amplification (complementary), [a way of] observing the human being that restricted medicine. In anthroposophy, I perceived that it expanded the approach to the human being. It (anthroposophy) surpassed the health aspect and could be used in every day life in other professions and as a way of life. So this is the difference; it is a way of life.

Both physicians and patients referenced the connection between health and recognition of

personhood that had been sidelined in favor of material conceptions of the self and of disease. Many took this association further connecting it to issues of responsibility on individual and societal (and medical) levels. The right to health, which is consistently cited by Brazilians as a marker of democratization as well as a mandate for state care, and citizen responsibility for health, bring both rights and responsibilities into the discussion of citizenship and governance. Many AM doctors saw the rise in chronic disease as a national and professional failure to support health and a growing burden on medical providers that would not be sustainably addressed if left unchecked. During our interview, one AM physician described these concerns as:

> Today we are living in disease; we do not live in health. So, in my view, this is a deviation, an inversion of what should happen. We perceive this, and nothing is going to resolve it because the (medical) system is unable to. Diabetes, hypertension, asthma … every chronic patient and a large majority of illnesses will increase, and the system will expand but there is no way to support this. So we have to ask the question, could it be that we are treating patients correctly? How can it be that a person can have an illness and spend their whole lives sick? If a patient develops hypertension at age 30 - that is no longer rare and used to be – then they will stay in the system for 70 years. How many are going to be born in this time that will also become hypertensive and also stay in the system? So there will never be a doctor who will be able to keep up with this approach. There will never be enough medication or money. So when something like this appears in this way (a young hypertensive patient), at minimum we need to ask the question "are we walking on the right path? Will this treatment truly resolve the issue?" I think this [question] is for the whole world – we need to change the form.

While both SUS and AM doctors cited notions of serving the public good through health-care, and in some sense the Brazilian democracy, AM doctors expressed frustrations with a perceived lack of in-depth prophylactic care and attention to *salutogenesis*. While critics of integrative care often assert that these forms of care reject basic biology and empirical science, both AM physicians (and nearly all patients) objected to the singular use of an empirical or materialist approach to *the person* in healthcare rather than empirical science itself. One AM physician framed the limited view of personhood as a roadblock to care particularly comprehensive prophylactic care as follows:

> You want to prevent disease, but how? The conventional vision does not prevent anything because there is no way to know the human being. The conventional version is like this: if the father has hypertension and the mother has hypertension than you are going to have to do physical exercise and diet your whole life in order to avoid hypertension. But it (health) comes from more than this: it comes from the (individual's) constitution, from a healthy way of dealing with life. The healthy way of thinking, how is this relationship, and what it is to be comes from a vision of the human being. So we [doctors) have to get out [of ourselves]; we have to know who is the human being in order to know what we are going to do with him/her. From the moment that we think the human being is just a head, or trunk or limbs, it will be impossible to maintain health this way. It is impossible because we are not just this. So the vision is limited, the human being is limited and the prevention using this image will be limited too.

The AM approach to patient care largely parallels a conventional biomedical approach with several key differences such as: length of consult, depth of the patient's history, and communication style. AM physicians still conduct a thorough physical exam that includes taking blood pressure, weight, etc. but approach patients differently. Since AM doctors envision the human beings according to a unique schema, their view of health and disease and disease etiology (as well as *salutogensis*) contrast with a conventional approach. The clues for a successful diagnosis lie not only in medical histories or patient descriptions of their symptoms but also in the patient's life context itself. This is why physicians privilege information from the life context in their diagnosis and will encourage patients to discuss their habits, sleep, relationships, general state of being or any other life events or influences that the patient is experiencing and sees as meaningful. A patient's individuality is largely reflected in their story, how they navigate their life context, and their history. In AM, there is no one-size-fits-all solution and AM treatment protocols were as individualized (and at times unique) as the patients themselves. AM's attention to individuality and a respect for individual autonomy positions doctors as partners with patients. This means patients have greater participation in their treatment plans as well as more responsibility to execute the treatment plan. Treatment also often calls for lifestyle changes, or changing habits.

When interviewing doctors and conducting participant observation in AM training, it became clear that AM physicians did not think of themselves as "lone wolves" in the healthcare landscape. They positioned themselves as members of a therapeutic alliance with (and for) their patients as well as their colleagues. AM places a considerable emphasis on the doctor-patient relationships, two-way communication and shared decision-making, which is reflected in the prolonged time dedicated to consultations (Hamre, et al. 2007; Heinz, et al. 2012). When asking physicians about what types of people sought AM care but did not stay matriculated, one physician acted out a consultation with a patient who after a few minutes, he counseled to seek another doctor. This patient arrived smoking, had heart complications and firmly asserted that while he knew smoking was negatively impacting his health, he wanted the physician to prescribe something to help his heart that did not require him to stop smoking. Another physician reported a similar instance of patient with heart disease who had been through numerous doctors and insisted he be cured in 28 days just through medication. Both physicians explained that according to an AM approach, health could not be achieved just through medicating the individual but through individual life changes and choices as small as shifting thought patterns to as large as quitting smoking. They counseled these patients that AM was likely not for them and refunded both patients.

Because AM's view of the person and the contextualization of health and disease within an individual's identity and life context, AM physicians can provide meaningful support through contextualizing illness within that patient's life path. That often empowers patients to take more active roles in managing their treatments and fosters patient satisfaction through a therapeutic alliance between doctor and patient. (Many patients may already be more motivated, and have expectations of personal learning and development, or to be active in their treatment and/or be

open to the impact of lifestyle on health and seek an AM doctor out for this reason (Esch, et al. 2008). This will be addressed in the following chapter. One doctor explained the balance between the idea of attending to a patient vs. attending to a disease by describing two different types of patients and why AM patients found the AM approach mobilizing:

> Patients like to be attended to. It is how they would like it to be, they would like to go to the doctor for themselves … Some patients are like "I have hypertension and so I take this medication", or they would like to be seen like … in the physical, astral (emotional), spiritual aspects of their life, to know their life and to relate [it] to the illness itself … or they desire this [approach] for their child. It's another thing … if people are responsible for public health these days, if they imagine that their children are well attended to, if they are certain that they will be well served, then this mobilizes something inside them.

Mobilization of the patient is integral to AM practice as AM requires active participation from its patients in order to forge a therapeutic alliance. These alliances requires a dynamic where patients bear more responsibility for treatment outcomes (and in some ways risk) and physicians must be able to relay medical information that translates into the patient's own language and concepts of heath/disease and decision making. It also means that physicians have to be attuned to what patients want and do not want, regardless of whether it is what physicians would recommend. This becomes particularly important when dealing with terminal patients who may choose quality of life over length of life.

Being attuned to patients on different levels or "bodies" and engaging in comprehensive communication also requires a certain degree of reflexivity and self-awareness on the part of the physician. AM medical students are exposed to self-awareness exercises designed to build reflexivity and empathy such as spending an entire day in a wheelchair and interviewing patients outside of a standard clinical assessment. They also take on real tasks and responsibilities early on in order to develop higher levels of commitment within a community of practice that models compassion and empathy (Scheffer, et al. 2013). Physicians also learn to connect with their

patients by taking extended histories that includes the constitutional and psychosocial aspects of health and diseases (Hamre, et al. 2014). Practitioners are trained to be attentive to patient narratives and beyond. This approach encourages patients to open up to physicians. Physicians will pay attention to many additional signs such as how the patient carries themselves/gait, their voice, and the skin (pallid vs. robust).

Part of AM training is what could be called "*inner work for caregivers to systematically develop and practice concentration, openness and resolution, as well as an awareness on their own thinking*" (Esch, et al. 2008). AM providers explained that this helped them avoid/minimize any personal biases interfering with qualified listening to the patient or diagnosis and treatment recommendations. The AM providers I observed in practice, interviewed, was treated by on several occasions or saw just speaking with patients in the hallways, all exhibited penetrating attention and unmovable calm that to the newcomer, used to a world of distractions, could feel piercing. They maintained a professional warmth that was both formal and reassuring. This demeanor was part of AM professional care, and I observed a marked difference in this demeanor when talking to them as a neighbor or researcher, versus talking to them as a patient myself. In the clinical setting, they had a way of making patients feel that when they were attending to a patient, that patient was the only person for miles.

While AM practitioners aim to create a peaceful and nurturing environment, the tranquility they strive to foster is often reflected in the physical clinical space itself. AM clinical spaces notably lack technological stimulus such as mobile phones, radios, or televisions. One AM physician, who had worked in SUS in Minas Gerias before she retired south, brought together the whole healthcare team to renovate the SUS health post, which had become rundown. Together, they transformed the post over the course of a weekend. They cleaned it out from top

to bottom, vacuuming, mopping, painting and decorating the post "*to bring the same care to the physical space that that they brought to their patients.*" This particular physician retired but years later was in the area for a medical conference and encountered several of the medical staff that she had trained. They invited her back to the health post and twenty or so patients she had treated years before came to visit her. She had been gone for 10 years.

At The Clinic, clinical space also had a personal atmosphere while maintaining a crisp professional ambiance. Physicians often rotated rooms or shared rooms with other practitioners who worked on alternate days. Each of these spaces was tranquil and inviting lacking the white light and cinder block sterility so often associated with clinical spaces. Physicians also did not use computers in these spaces. All physicians took notes on paper (rather than a tablet or computer) and were able to better maintain eye contact without electronic devices in the exam room itself. Concepts like "mirroring" – where patients become aware of themselves, their capacities and their values as a consequence of being in a supportive and peaceful environment (low stimulation), are integral to the AM approach to care. Clinical space was not a place where one was stripped of identity in favor of a clinical label (such as a disease or symptom). Rather it is a space where patients are explicitly encouraged to share their identity, feelings, and suffering. Within this space, AM providers also oppose a hierarchy between themselves and their patients creating a clinical space that feels like a homecoming rather than an alien environment (Arman, et al. 2008). This continuously struck me as patients entered the premises at The Clinic. At The Clinic, the exam rooms are on the second floor and physicians almost always came down the two flights of stairs to greet their patients and their families with warmth and encouragement all day long. Patients, who were shy, in distress or very young, seemed to consistently display a marked shift in their body posture and ease of communication when greeted this way.

6.7 AM PERSONHOOD IN PRACTICE

As many physicians have pointed out, "*academic medicine is characterized by a peculiar paradox. On the one hand the scientific achievements since the 19th and 20th centuries are unparalleled in history. On the other hand, patients are increasingly dissatisfied*" (Heusser, et al. 2012). Efforts to address the human side of healthcare, however, have often attempted to inject humanities into science to add a "humanistic touch" that anthroposophists argue misses the mark, because like not being able to "see the forest for the trees," biomedicine medicine is often unable to see the person through the biology (Heusser, et al. 2012). In his *Lancet* article in 2000, John Martin captured this when he stated, *"perhaps the greatest problem of the next 100 years in biology will be to understand what makes the human being a human being"* (2000).

AM's conception of the human being as both threefold and fourfold lays a framework to approach health and disease through an institutionalized view of personhood and its role in medicine. AM treatment is much more than biomedicine with psychological counseling and emotional understanding or therapy juxtaposed at the end. AM doctors distinguish themselves from conventional medicine (and other forms of integrative medicine) because of their focus on their expanded view of the human being and their approach to treating the whole person according to this expanded view. One of the clinic doctors explained this saying:

> No one practices as an anthropsophic physician without becoming a doctor (MD). So we can talk about the results of medicine that only looks at disease and a medicine that see the human being in their constitution, their biography, and their purpose/aspirations.

In Anthroposophy, personhood is central to understanding not only why someone is ill but also the course of action to restore to health. Illness, however, is not posed as a polarity to health so much it is seen as a teaching and learning opportunity – a reflection of how that

particular patient's being and "destiny" is unfolding/needs to unfold. Illness is important to human beings' mastering the human condition and their individual life path. This is why understanding personhood is integral to patient care to ensure those lessons are learned by the patient (to avoid remaining ill or becoming chronically ill) rather than having the "lesson" removed by the doctor. Anthroposophy places considerable emphasis on the unique path and makeup of each individual and how their personhood shapes and is shaped by their physical body.

An example of how this philosophy is transformed into practice can be seen in the AM approach to fevers in children in particular. Fevers (heat) are considered manifestations of the ego or the spirit self. (A corpse, for example, lacks warmth.) In AM, fevers are particularly important for child development for several reasons. As a manifestation of the ego, it is an opportunity for the child to shape their physical form (transform inherited genetic material into a form that their own individuality also permeates and shapes) and affirm their will to be fully incarnated living beings. During a fever, the ego body is thought to be working on the physical body to not only eliminate a foreign invader such as a virus or bacteria, but also to shape the body itself. The ego in this example would be akin to a sculptor and the body the medium worked upon. To suppress the fever also means suppressing this process and development of the child. For this reason, treatment must be considered in the context of the particular patient's personhood and life context and the processes that need to unfold for them to continue to develop. Fevers are carefully monitored and AM physicians will not universally recommend letting a child's fever run its course if children are below the age of 6 months, have certain risk factors like epilepsy or are running extraordinarily high fevers. The idea of fevers as functional for personal development heavily contrasts the conventional approach to use antipyretics even in

children with low risk of convulsions (generally after 6 months of age with lower grade fevers) (Foundations in Anthroposophy Course 2015).

Illness has purpose and so physicians need to be clear to a certain extent what that purpose is and how able the patients are to meet illness on their own. AM physicians treat the human being, physical body included, as an intelligent system that if supported properly can heal itself. “Constitutional” remedies help fortify and activate the patient’s own forces to address illness be it anxiety, a UTI, or a sore throat. Not all patients are able to heal themselves with constitutional remedies and require treatment that directly targets the disease itself, however. When discussing how AM physicians make these treatment decisions with their patients, one physician explained it using the example of a pediatric patient he was treating with antibiotics for a bacterial infection. The infant had come in very sick, and frail and had a high fever. He explained that to give a constitutional remedy to any individual who had low vitality would be directing the body to draw on forces it did not have at its disposal. In cases where patients were too weak to health themselves, giving a constitutional remedy could be fatal just like “flooring it” in a car with no gas. These cases required allopathic intervention such as antibiotics, to clear the infection for the patient. Follow-up treatment could also include remedies to assist in developing that patient’s vitality and resilience so the patient would be better equipped to meet future challenges.

Cancer patients also provided an important window into AM’s view of the role of illness in the life context of the patient and the mixture of biomedical and AM treatments. Many AM physicians encourage their patients to go through allopathic cancer regimens with additional AM regimens like mistletoe as well as other remedies to support the patient through taxing treatments like radiation, surgery and chemotherapy. Accompanying treatment for cancer patients often

involved additional interventions like biographical counseling and art therapy. Biographic counseling in particular was an important opportunity for patients to understand their illness within the framework of their own life context. Biographic counseling usually consists of 7 sessions in which patients are asked to examine particular points in their lives, which are expressed in watercolor painting and discussed and reviewed together with their counselor along the way. There were several instances where patients brought their own drawings (both from biographical counseling and otherwise) to their physicians, because they felt it would give the physician a better understanding of who they were as people particularly when depicting important life events, aspirations, goals, and people, in their lives.

AM's approach to death was also notably different and could be seen in how they cared for the terminally ill. While biomedicine often treats death as the ultimate failure or a moral failure, the goal in AM is more nuanced than keeping someone alive – which is still very much important – since it also incorporates spirituality into its practice. During a presentation at an AM cancer treatment summit in Belo Horizonte, one physician presented the paintings and story of one such terminally ill breast cancer patient. The patient had spent most of her life in a well-paid and high stress position that had taken up most of her time and interest. After being diagnosed with cancer, she realized there were many aspects of herself and her interests she had been unable to explore. Through art therapy and biographical work, she was able to reshape her life and process her story and give her cancer meaning within that story in a way that brought her closure and satisfaction in spite of her terminal diagnosis. It allowed her to regain a sense of control over her condition and her end of life choices. Her treatment had not been about how to keep her alive as long as possible. It had instead enabled her to maximize her quality of life, dignity and integrity, which required the physician to acknowledge what her patient wanted even

if that meant a shorter life. While the physician found this visibly difficult, she also acknowledged it was in line with respecting the rights and responsibilities of patients and doctors and the role of illness and its meaning in that patient's life.

6.8 CONCLUSIONS

Throughout this chapter, there have been examples of how AM conceptualizes the person, and how this translates into a unique approach to patient care and treatment. The AM ontology of personhood and its recognition of the highly individualized nature of that personhood as well as its role in creating health or disease is reflected in the treatment prescribed, and in its patient care. AM's attention to patient autonomy and sharing of risk and responsibility in decision making set the stage for patients to understand who they are and what they are experiencing (particularly illness), in an AM framework that expands the definition of being human and the rights and responsibilities that can be drawn from this expanded definition. For a physician trained in AM treatment, a patient's individuality is expressed at all levels of the four-fold and three-fold conception of the person and therefore requires treatment to address all levels or aspects of the human being. Heusser et. al. captures this in his article adeptly stating:

> AM therapy is addressed at different systemic levels. For example, surgery and radiotherapy are targeted at the physical elimination of tumor tissue; conventional pharmacotherapy or pharmacologically active phytotherapy can be aimed at eliciting processes on different levels (physical, organic, psychic or spiritual), depending on their lawful relations to them. Homeopathically potentized preparations are used to activate life processes, psychological or spiritual forces. Non-pharmacological treatments are also addressed at different systemic levels: physiotherapy to improve physical functions of the musculoskeletal system, therapeutic eurythmy, an anthroposophic mind-body movement concept, is used to exert effects through life processes; psychotherapy or art therapies such as music, painting or modeling affect emotional functions; and cognitive communication strategies are used to support the individuals' own coping strategies, search for meaning or spiritual resources (Heusser, et al. 2012).

Physicians encourage their patients to share who they are in the exam room from their family roles, to jobs, to beliefs, medical and family histories, etc. Then the physician uses this information to pinpoint the root of the illness. Addressing the imbalance can be thought of as a transformative process such that through art, or biography, or conversation, the patient is able to integrate a (bio)medical diagnosis within their life context. While physicians stress respect for their patient's autonomy they certainly do not give extended philosophical explanations for illness. Physicians are there for their medical expertise and to provide a means to integrate the experience and ailments of the physical body into a more personalized and digestible framework of the individual's life context. AM has the potential to integrate how patients view themselves and their illness experience, translating a medical diagnosis into their own life context. In this way, patients and doctors coauthor personhood (see chapter 5).

Patients who have been dislocated from their life contexts in the conventional biomedical setting have the opportunity (and are actively encouraged) to bring their life context into clinical space. AM clinical space then becomes an arena where meaning can be associated with malady, where the "why me" and "why this illness" can be addressed and jointly explored by physician and patients, where patients are the experts in their own life context and physicians are the clinical experts. AM doctors solicit participation and information from patients to bridge life context and the personhood that is derived from said context, and connect it to root cause for disease treatment and a future approach to health. In this way, an AM visit can be thought of as the intersection of life context, personhood and health. This intersection is generated by co-creating personhood through diagnosis and treatment processes. Through tying personhood (rights and responsibilities) to life context and to health, AM doctors are well positioned to renegotiate or challenge public health authority by decoupling truth from conventional authority

and the rights and responsibilities generated through the SUS medical system/Brazilian Constitution. This intersection is where non-conventional biological (Brazilian) citizens can and do refashion the rights and responsibilities of the "New Brazilian biocitizen" through their medical choices (see chapter 5).

7.0 CHAPTER 5: THE INTERSECTION OF PERSONHOOD, BIOCITIZENSHIP AND PATIENT CHOICE

7.1 INTRODUCTION

Choice has been considered in a number of different ways in order to understand how patients navigate and participate in various forms of healthcare. Models like *folk dichotomy theory, efficacy testing, shotgun therapies, chronic vs acute, relative wealth, relative acculturation* and *innovation and theory* have struggled to be generalizable (Colson 1971; Garro 1998; Myntti 1988; Schwartz 1969)(Hsu 1955; Ubel 1966; Madsen 1960; Torey 1968; Erasmus 1952 and Schwartz 1969). This research address the role of personhood in choice and expands upon Garro's work and his assertion that decision making included "*the jointly cultural, personal, social, and cognitive constructive processes through which meaning is conferred upon the occurrence of illness*" (Garro 1998). It also expands upon Crandon-Malamud's push for considerations of patient choice to include identity and status and Kleinman's focus on patient negotiation (Crandon 1986; Katon and Kleinman 1981). AM health seeking behavior represents an interesting case because it often violates the economic and social considerations or other forms of "rational" decision making because it is generally more expensive and less accessible. It is also less known than other forms of integrative care with little dissemination of its efficacy outside of individual experiences and anthropsophic community circles.

In this chapter, I show how AM patients are seeking a different model of engagement – a different form of patient care than their SUS counterparts. AM patients do not reject biomedicine. On the contrary, they used it and often continued to use it for exams, treatments and interventions as directed by their AM doctors. For some, AM physicians' literacy in biomedicine, was reassuring and they trusted it more than forms of integrative healthcare like acupuncture of herbalism. Like SUS patients, they expressed consistent assertions of the right to health and the need to be responsible for one's own health. The significant difference between AM patients and SUS patients was how they deployed these understandings of responsibility and rights as Brazilian biocitizens. AM patients were looking for a different paradigm in medicine that could align with their views of their own personhood. They typically rejected integrative healthcare in SUS since these modes of care were often applied according to a biomedical paradigm that did not align with their own ontology of personhood. Choosing to participate in AM reinforced a non-conventional view of biocitizenship encapsulated in SUS and Brazil's 1988 constitution, reinterpreting the rights and responsibilities of patients as biocitizens. AM acknowledged how patients saw themselves and their overall life context (Mishler 1984). AM allowed them to express themselves in the voice of their lifeworld and doctors used the voice of the lifeworld as well rather than medical language with cooperative power sharing and decision making. This model of care aligned (and likely informed) with a non-convectional view of personhood and biocitizenship.

Anthroposophic patients are an important example for understanding healthcare seeking strategies particularly since they have a mixed approach to obtaining care. Patients often combined services from both SUS and AM resources. SUS was primarily used for diagnostics since AM patients generally cited believing that biomedicine was both necessary and had

valuable and effective methods of addressing pathology and injury especially for acute care like broken bones or appendicitis. Most if not all AM patients acknowledged the need for biomedicine, which is not surprising when one considers that all AM physicians are MDs. What AM patients objected to was the exclusion of their lifeworld's and what they perceived as the overuse of allopathic medications. They saw and were socialized in AM to see illness as purposive. One did not become ill randomly but because the patient had in some way become out of balance. AM patients spoke frequently about the need to find balance in their routine, in their diet, in their emotional and family lives and even in giving time to activities like art, sports, or singing, that one could describe as "soul nourishing." These activities allowed patients to maintain their own equilibrium.

While some patients might have been further motivated to seek and use AM after negative experiences with biomedicine and allopathic medications, a great deal of the draw to AM came from a sense of needing help to restore equilibrium oneself rather than restore it through "artificial" intervention that commandeered the healing process or resolved the problem for the patient. Patients often viewed "artificial" interventions like biomedicine as effective on the physical level but in some way cheated patients out of a lesson to be learned. This AM patient, for example, expressed his use of SUS and how despite getting a health problem resolved by a SUS physician, he still felt unsatisfied:

> The last time I went to the [biomedical doctor] was when I lost my voice. So, the doctor asked me – what is happening? And I said "I'm losing my voice. I don't have my voice and I need to talk." I simply said this to him "resolve this problem; I need it resolved." And he arrived, analyzed the problem, wrote me a prescription, applied it and sent me on my way and I'm still alive to speak another day (laughs). He solved my problem. I think on the occasion if I had more time to improve my voice, I would have simply rested in a room, but because of my professional obligation I had to compromise. He resolved the issue. The consult was very quick … he solved the problem I had on that occasion quickly. I'm grateful for that but I do not like to have this type of interference in my body every time I have a problem. I think it (the medication) is too harsh but on that occasion, it resolved the problem.

This patient chose biomedical care because he needed the problem resolved expediently due to being the lead speaker at a summit. He would have preferred to heal on his own but recognized biomedicine often had a quicker fix to address his symptom. This kind of intervention, however, did not align with the AM patient's desired approach to engaging illness.

Interference in the body and the reticence to be medicated with "artificial" drugs were a ubiquitous theme in AM patient narratives. Many patients did not trust other forms of integrative medicine either and relied on their AM physicians and sometimes family home remedies for their wellness needs. Both of these themes will be explored in more depth within this chapter. It is important to note, however, that the rejection of biomedicine as the primary form of care extended far beyond the desire to avoid "artificial" interventions in the body. It was largely in part due to a desire to be seen under a different kind of medical gaze, and to be included in the medical space the way they saw themselves, rather than purely within the context of their medical issue. Patients who had been coming to AM physicians for decades, like the one cited below, did not always recall with great clarity who they had seen or why they had seen them when they first started using AM. They did, however, remember why they had continued to use AM:

> I once met a person who had to go to the Tobias clinic in São Paulo and did not know where it was and I had to take that person there. And I was very impressed with the few words that the doctor spoke in front of me and from there I started to seek that kind of medicine for myself. Why? Because I felt the way that the doctor looked at the patient was very comprehensive ... and this person I took there, [in the consult] she talked about things in her life that for me was beyond what would generally be a conversation between a doctor and a patient. So there was this opening to consider life as a whole, which enchanted me.

Throughout this chapter, I will explore how AM patients, like the one above, seek care that sees and treats them according to a different paradigm that uses many of the same therapeutic tools as biomedicine, but frames the doctor-patient relationship and the human being quite differently. This chapter will show how patient choices to participate in AM are informed

by a desire to be treated in a medical system that aligns with their understandings of their own personhood. I will conclude with how participating in a medical system that provides an alternate view of personhood shapes the rights and responsibilities patients believe they (and their doctors) have as Brazilian biocitizens.

7.2 VIEWS OF SUS HEALTHCARE: ALIGNING ILLNESS AND TREATMENT

SUS and AM patients shared many concerns about health and illness and medical care but for AM patients, these concerns were shaped by a different understanding of the body and of the self (personhood). The body served as a site of negotiation and transforming of social contexts and the self as well as the redefinition of legitimacy and control (Crandon-Malamud 1991; Greenhalgh and Winckler 2005; McNay 2009). These concerns shaped the expectation for what patients anticipated from their doctors, from their treatment and from themselves.

AM patients often shared a general distrust or dislike of allopathic medications for several reasons and believed them to be strong with potentially harmful side effects. Medication is often used in the name of the protection of life yet it can also be cast as an intervention in the biopolitics of patients through the dynamic of authority (Foucault 1963; Petryna 2004b). AM patients' rejection of another's control or intervention on their body, particularly through medications can be cast as a rejection of biopower wielded by the State through SUS as well as a demand for rights (Foucault 1963; Petryna 2004b; Rabinow and Rose 2006). Several SUS patients shared the same sentiment of being displeased with a "one size fits all" approach often found in biomedicine and to being medicated although to a much smaller degree than AM patients. These patients often sought other forms of integrated healthcare within SUS as well as

outside of it. This SUS patient for example had Hepatitis B but after trying the treatment, was dissatisfied with the approach and felt compelled to seek help from different medical modalities:

> I had this intuition, which said everyone has a liver and doctors always treat the liver the same and forget that around each liver there is a different human being and they do not treat that human being. The intuition said that it was up to me to look for holistic therapies, alternative therapies; I did not even know what they might be. And that's when I told the doctor I would not take the medicine [for Hepatitis B]. My sister, who is a doctor was horrified, said I had to take it. The doctor said I would have cirrhosis and would die if I did not take it and I took the risk and I did not take the medicine.

This patient continued to use SUS for all her exams and monitoring of the virus but continued to seek assistance from nutritionists, *Spiritist* practitioners, *biodança* and reiki with positive results. She lowered her viral levels enough that she did not need to take the antiviral medication and had been maintaining these low levels for several years. Her choice to reject the biomedical medication stemmed from a belief that she was the one responsible for her own well-being and that she it was her responsibility to find and use what would make her well. She had a right to health and sought care that she believed best aligned her individuality and with that mandate.

The Hepatitis B patient is an indication that AM patients were not alone in their desire for a more individualized approach to health and disease applying the concept of responsibility to maintain one's health by utilizing resources outside of SUS although AM patients expressed this from several different lanes and more consistently that their SUS counterparts. That being said, while many SUS patients went to SUS to get a problem fixed, many either described understanding that biomedicine was symptom focused rather than root cause focused. Others expressed a purely utilitarian interest in SUS – that the system was there when a problem materialized, and were satisfied if the physician fixed said problem as expediently as possible. This translated into some differences in how AM and SUS patients defined the rights and responsibilities of patients and their doctors and their expectations for care.

For AM patients, there was a sense of meaning in disease and health that was intimately tied to what it meant to be human with an individual destiny. These ideas of what was "natural"

and "unnatural" were deeply tied to notions of what was safe and unsafe for both SUS and AM patients but where SUS and AM patients differed was in the idea that medication might cheat the patients out of the lessons of the illness. Patients in both modalities worried about the toxins or side effects in biomedicine although this was significantly more common in AM patients. One SUS physician was an AM patient and specifically sought out AM because she did not want to use allopathic medications. When she was asked why she would not take many of the medications she prescribed for her own patients she answered:

> It's because in truth, because I am a doctor and it's like this … I've lived the side effects of the medications I give. Even at this point in time the medications for asthma for example are medications that can make you … they leave people tachycardic right? I already am tachycardic and I don't want this for myself. So, I don't want conventional treatment because of the adverse effects of conventional treatment.

While she named the side effects of asthma medication, this particular patient was seeking treatment for hypertension and high glucose levels at The Clinic. She also self-treated certain things allopathically like UTIs and seemed averse to treating any kind of infections with anything other than antibiotics, which likely stemmed from her general distrust of PICs after seeing patients who had treated their infections without antibiotics and had complications.

Unlike most AM patients, the patient quoted abov ecoded certain illnesses as within the realm of AM *or* biomedicine. She also made distinctions between certain biomedical medications as desirable or undesirable to take (safe or unsafe) where AM patients classified allopathic medications consistently as a group. Ironically several patients explained that they had become believers in AM when they had UTI's they could not resolve with antibiotics but had complete success with an AM protocol for their infections. I myself was treated at the clinic for a UTI and intestinal infections without antibiotics on two separate occasions quite successfully with AM medication and two medicinal teas (Figure 2).

Figure 2. An AM prescription for a UTI and stress. From left to right: AM tinctures to fortify the constitution and eliminate infection, Horsetail tea & Chamomile tea

For both SUS and AM patients, the desire to avoid taking allopathic medications was particularly pronounced if these treatments were something that patients had to take for long periods of time like cholesterol medications or insulin. While SUS patients were concerned about a perceived toxicity of these drugs to a certain extent, AM patients often voiced their resistance to being medicated in terms of being dependent or reliant on an external intervention for extended periods of time. Patients often referred to concerns about becoming "dependent" on allopathic drugs in the sense that they would need the medication to be well rather than

becoming dependent on a drug in the habit forming or addiction sense of the term "dependent." This concern was amplified for anti-depressants, sleep aids or any medications for their children.

For AM and SUS patients, it was more common to have sought PIC therapies for their children rather than for themselves at least initially. Homeopathy, for example, was often considered more effective or suitable for children ,who were thought to be more susceptible to side effects from allopathic medications. Children were also considered more receptive to treatments like homeopathy because they had not had years of allopathic medications that both SUS and AM patients frequently thought had decreased the effectiveness of these medications on adults. Treating children with "less strong" or "natural" medications like homeopathy was therefore, also a way to prevent children from building up a kind of tolerance or immunity to allopathic medications. Home remedies in the form of teas and certain foods were often the method of choice to treat children as well especially for colds, coughs, sore throats, diarrhea and stomach aches.

Although adult patients in AM and SUS reported similar healthcare seeking strategies for their children, and concerns over the toxicity/side effects of allopathic medications, they had significant differences in healthcare seeking strategies. SUS patients were more likely to seek healthcare only in the event of an acute health event especially if they were men. SUS patients often reported going to health posts "*if I have something to show them.*" SUS patients also sought care, although less frequently, for exams like STI testing, for follow-ups for chronic conditions, cancer screenings, vaccinations, and some for checkups. Regular users of SUS were more likely to express satisfaction with the services they received especially if they had previous experience with SUS in other parts of the country. One such patient who had moved from São Paulo, explained that the services in Florianópolis were significantly better than other cities. Her son

had a chronic illness and so they used services regularly for a number of his needs. She also went for checkups and routine care herself. While the wait could be a bit long, she was adamant that the services they received and the care she and her son were given were extraordinary especially since they were free:

> Well, since I came to live in Florianópolis - I'm from São Paulo, - but since I came to live here in Florianópolis, I use the Unified Health System (SUS) for everything. I did all my prenatal healthcare here. I was very well taken care of; I had no complaints; I do not have any complaints about it … but the care my father received, that was the most important thing. He had cancer and he had all the treatment done by SUS both the examinations, the medicine that he needed he also got for free through public healthcare. It costs more than seven thousand *reais* - the medicine he had to use - and then he got it through SUS, which gives that drug free of charge. The experience I have [in SUS] is pretty great in that sense so, whenever I need something, not only consultations, I also use the hospitals, the UPA's take care of it.

When describing her experiences in care, the patient quoted above always included that she had nothing to complain about. When she had a minor problem with her ear, she felt she had been well treated even though the concern had not been grave. The physician had seen her quickly (the visit had been scheduled a week in advance), cleaned out her ear and given her medication. She felt the ear had become inflamed due to her own actions of itching it and was somewhat embarrassed that she had "caused" the problem. She also explained that while the physician had asked her if she had any other concerns or things she wanted checked, the patient felt that since she had been fit in so quickly that she should not ask for anything else and that none of her concerns, like renewing her contraceptives, as pressing enough to bother the doctor with.

The patient who had moved from São Paulo illustrated many of the same qualities and expectations of her SUS counterparts who often qualified care in terms of whether their health condition had been solved and also how quickly they had been seen. Considerations of getting "free" care were more likely to appear in SUS patients whereas AM patients were more likely to feel any care they received in SUS was owed to them rather than some form of "charity."

Patients in general wove together the imagination of the state and the provision of universal healthcare in the way they understood the relationship of top down process' relationships with the local institutions. This imagination of the state and the view of an interactive layering of government and people are important for maintaining "the mandate of the people" as well as creating a national imagination of the citizen (Ferguson and Gupta 2002). Both AM and SUS patients incorporated the role of individual responsibility as part of this relationship between the state and the citizen, but framed and deployed them differently. While Foucault showed how populations are governed by institutions, agencies (both state and private), and the norms and identities that these entities construct, this chapter shows how the norms can be refashioned or counteracted using "outside" institutions or agencies (Foucault 1990).

The fact that the system was "free" seemed to be a dividing factor between SUS and AM patients. While SUS patients acknowledged it was not entirely free since they paid taxes to have SUS, many were proud of the fact that Brazil had a public system. SUS patients tended to quote the "free" nature of the system as grounds for being more patient and understanding of its limitations whereas AM patients were more likely to reference the fact that health was a right of citizenship, and therefore inadequate service was a betrayal of this right to a certain degree. Both groups of patients acknowledged the importance of such a system for the country itself, however.

SUS patients who used the system more regularly were more likely to be proud of it as a national accomplishment than their fellow SUS users who only used it in cases of emergency. The fact that many people from outside of the region utilized the system as well as the ranges of social classes of users was referenced to illustrate that while SUS had some limitations, it was functioning well in the region. Many proclaimed that SUS was studied around the world and that there was not a system like it anywhere else. One patient explained that she had been injured

abroad and had to sell many of her possessions in order to pay the medical bills. This would not happen in Brazil to citizens or anyone legally in the county, making SUS a superior system and marker of social consciousness not unlike how Cuba's use of the medical system was used as a benchmark of the country's evolution (Brotherton 2012).

One should note many of the participating patients had private healthcare plans at one point or another in their lifetime especially if they had lived in other cities. These plans were primarily used to obtain exams or see specialists since one tended to have to wait more time for these services in SUS. The line between public and private gets somewhat blended, however, since many specialists have public and private practices. Some patients who had physicians in SUS used private plans to continue with those physicians in their private practices in order to maintain continuity of care such as follow up after a major motor vehicle accident or heart surgery. Besides waiting time, SUS patients did not make much of a distinction between private and public medical care and several said they saw no difference beyond wait time or that SUS physicians were superior to their private counterparts. AM patients generally had all of their exams done in SUS, but coordinated care including the interpretation of their exams through their AM physicians.

Despite the fact that many SUS patients lauded SUS as a milestone in democratic development, they often pointed out the idiosyncratic nature of the health posts and quality of care when they explained which posts and hospitals they went to and why. Many of the SUS patients regularly were treated by nurses at the health post sometimes for minor issues or for PICs services. One patient who never went to the health post because she did not like waiting to be seen started going to the health post for applications of heated seeds for knee inflammation as well as floral remedies. She was quite pleased with the results and with the nurse who had

changed her view of the health post. Several SUS patients expressed similar sentiments and had posts, doctors, and nurses they preferred. The success of the health post was regularly attributed to the staff who worked there rather than anything from the system at large. One patient described a post as preferable because it had a dedicated nurse there who never failed to be there for her patients rain or shine.

7.3 THE DOCTOR PATIENT RELATIONSHIP AND RIGHTS BASED IN PERSONHOOD

Some of the different expectations of what providers should offer and patients should do were rooted in how patients viewed the legacy of the healthcare system in Brazil's overall history as well as its role in a continually stratified society. Some patients identified the discrepancy between what providers should offer and expect as a result the contrast in social class of between patients many doctors for example. One SUS patient who had explored a number of PICs in addition to Spiritism explained this difference:

> [To address the divide between patients and doctors] I think I would start before the health system in the training of doctors. I think we have to start from there since it is already in the doctor's training. The doctor in training should be more aware that he will treat human beings, right? Generally, who are these doctors? Who are the people who pass into the medical courses? Rich, wealthy boys and girls who have studied in good colleges and who have always had everything and often never had contact with human suffering, with human needs. But it is more difficult to say that these doctors … that they have to be prepared for what they are going to find and how they can act in the best way.

The statement above is striking particularly since this patient's sister was a physician in SUS and a good friend was also a nurse. Yet physicians were often cast as a somewhat removed "class" of people in the eyes of some SUS patients and a few SUS physicians as well. The removal of SUS physicians from patients lent itself more to a dynamic where patients expressed

a reticence to “bother” the medical staff or that they should not access the system unless there was an imminent need to. The right to health was frequently attached to ideas around self-care and responsibility that also underpinned assertions about what services patients should use and how they should use them. It also underpinned assertions about how physicians and patients should operate around one another in the socio-medical space. One SUS patientwho was a doctoral student in the area expressed this dynamic below:

> We have to learn to take care of ourselves, right? And after we know it, we have to teach others, too. As for public health, I think that it starts with education. If people know how to take better care of themselves, they're going to have less problems, right? And I think you have to inspire this in people -- to know that they too can cure many things themselves when they look for the right foods, the teas, the juices, the way to cook the food, right? And ... and then that's it, instead of politicians stealing so much, using more to, to improve hospitals (laughs)), to hire more doctors.

Woven into her considerations of the quality of care given was an idea of needing to minimize the cost to the system. This was significant especially with the inclusion of PICs.

PICs were introduced as a cost-effective way to expand access to services and cycle out patients who were not getting their healthcare needs addressed to other avenues of treatment that were often attractive because they were less invasive. SUS patients often accessed these services (if they knew they had them at the post) for the conditions they did not want to “bother” the system with. A small few sought care at the *Spiritist* hospital, which utilized much of the symbolism of the biomedical hospital including white coats and consults. Others used nutrition to help with inflammation, weight loss and detoxification. Yoga and meditation were typically sought for stress management, and acupuncture was typically used to address pain as well as complaints of sleeplessness, stress, or migraines.

SUS patients used PICs in a very biomedical way. Acupuncture was considered a pain management tool, for example, rather than a form of medicine that could address a much wider array of health concerns. Perhaps this categorization of PICs with certain illness categories was a

reproduction of how SUS physicians were trained to apply PICs. SUS patients often sought these services for specific conditions when they were seeking them within SUS facilities. If they accessed PICs privately, they acknowledged that the form of care was different. Acupuncture in the system for example, was different than acupuncture outside of the system. One patient who had acupuncture both in SUS and outside of it for recovery after a motor vehicle accident explained that while he thought the care he received in SUS was exemplary and spoke highly of his physicians including a SUS physician who applied acupuncture, he still sought acupuncture outside of SUS:

> I think when you do the SUS treatment, unfortunately people have a short appointment time to serve you and there are many people waiting in line. The process is faster, more dynamic when you do treatment with the acupuncturist who attends privately. They are calmer. They have more time to talk and more energy. That's the difference that I feel. He attends me in a little more personalized way. In SUS, it seems that they have an equal standard for all people; they follow, a technique, a similar pattern, the same method for all people.

This patient viewed acupuncture applied in SUS as different than acupuncture outside of SUS. Private practitioners applied a more personal approach rather than what he viewed as a standard usage in SUS. He believed both were effective but that in order to be truly well, he had to seek outside care with a more personalized approach.

7.3.1 Rights and responsibilities of physicians according to SUS patients

Differences in expectations for care were often illustrated in the diverse descriptions of the qualities and habits of the "ideal" physician. The view of the ideal doctor greatly colored SUS patients' perceptions of whether they were receiving the care they deserved as citizens. When the patient referenced earlier in this chapter who had moved from São Paulo described her ideal doctor, she also used several examples of past physicians including many Cuban doctors, who

"*had been very attentive, but perhaps could have listened more*." Certain aspects of care were considered "extras" versus "essential." Being seen quickly and having one's problem fixed was the general SUS patient standard of care. AM patients, as this chapter will show, looked for a different standard of care. Both groups might cite wanting a physician who was "attentive." There was a difference, however, in how SUS patients were qualifying "attentive" as a means of problem solving and actually treating you versus qualified listening to patients and their concerns.

When SUS patients were asked to describe the ideal physician, SUS patients gave a variety of answers that ranged from wanting physicians to be good looking, competent and attentive to cooperating with other healthcare personnel to give them the best possible care. SUS patients expressed the importance of having someone attend to patients with confidence, professionalism and experience. Quality care was often framed as being attended to quickly and being provided the correct diagnosis. Good doctors should ask for the appropriate exams, talk to other specialists about your case and not be overly concerned with making money. The ideal doctor also needed to be dedicated to the profession. This was not only linked to not being motivated by financial gain but also observant of individual needs. While the following patient said she had received quality care in Florianópolis and Curitiba in SUS for a variety of conditions as well as her daughter who had several special health needs, she, like several SUS patients, identified a systematization of care that was one size fits all:

> I think the concern should be with the patient; I think it's the first item. So, I guess that from there the rest comes through, right? It brings everything together. The affection, the dedication, I think even the love for the profession … I think it does everything. And today I see within medicine, unfortunately, is more concerned about money than, than love for the profession itself. And today, there is a standard of care within the SUS, which is all very much automatic, right. You need the same tests, the same medicines. The same drugs are always prescribed for people; they do not escape this. Omeprazole for the stomach, for heartburn ... it's always ... you take a SUS staff member and you will see that they do not seek, let's suppose, have better, more specific treatments. What the SUS gives you is X; it will not give you XY.

The above patient narrative adeptly shows a perception of the formulaic like nature of care in SUS. Like the patient who sought acupuncture outside SUS as well as internally, she explains that the care is good, but does not always feel personalized. "Good" care meant being treated and having a problem solved, yet despite this, she felt that something was still missing from care that perhaps could have further elevated the quality of care.

Unlike AM patients, most SUS patients made the distinction between "good doctors" in terms of technical care as being separate from doctors who also were exemplary in terms of their interpersonal care. There were doctors who would see you quickly and try to address your concerns but they would not "look" at you because they had a line of people to see and were typing their notes looking at a screen. These doctors were not dismissed as bad doctors by any means. The view of the ideal doctor often had more to do with how thorough the technical care was rather than interpersonal engagement or lifeworld context inclusion. This patient for example, describes a somewhat cut and dry description of the ideal physician and quality care:

> I think the ideal doctor would be the one who does a general checkup on you, takes your blood pressure, checks if you have an eye problem, looks in the eye to sees if you have anemia. They should give you a good checkup done with a blood test. For you to have something like this today in the SUS, you will have to arrive there in very bad condition for them to do this. If I arrive with a little cold, they don't do any exams. I get there, they look at me and I'm gone … And they give you a prescription and you can go.

Several pieces of this narrative characterize SUS interactions with the system. The patient, who a number of chronic conditions from arthritis to high blood pressure, believes quality care is receiving routine checks and exams and does not name any interpersonal qualities or aspects of a physician's approach to her care. Instead she focused on the process of a consult and the measurements. The standard of care she expects, is tied to the routine of a classic clinical interview. She also feels entitled to services like bloodwork when these are not necessarily medically needed – a trend that led one SUS physician to put a cartoon satirizing patients' use of

Google for self-diagnosis on the consult door. She was still cognizant of the frustration she encountered when she wanted these kinds of treatments and doctors did not want to provide them. During our interview, she explained shifting to different health post physicians she did not want SUS doctors to become frustrated with her when they could not address her concerns the way she wanted them addressed.

The patient in the narrative above echoes one of the patterns SUS physicians complained about: the expectation that patients needed exams to be receiving quality care. This SUS patient aligns more clearly with complaints by SUS physicians and fellow SUS patients that some patients use the system too much for things they can/should take care of themselves. On the onehand patients cast avoiding SUS and using other forms of medicine like PICs as responsible and as a means of ensuring one's own health and not taxing the system. On the other hand, being responsible could also be mean showing up and using the services that were guaranteed to citizens in order to ensure that one was not sick (and still a productive citizen) or would not become more sick and burden the system. Both of these approaches deploy the same neoliberal logic of individual responsibility, autonomy and rights embedded in vital terms but have different expectations for the system (Greenhalgh and Winckler 2005; McNay 2009; Rabinow and Rose 2006; Shaw 2012). AM patients were far more likely to expect the system to offer them certain forms of care beyond technical care as well as be more invested in their own health /responsibility for their own well-being. In both cases, one can see how the rights and responsibilities of patients and doctors are informed by their expectations for the system itself and how the logic of citizenship and responsibility are being deployed.

The logic of individual responsibility for doctors and patients and the role of the healthcare system were inextricably tied together for both AM and SUS patients. The SUS

patient below teases out aspects of how these factors are interrelated as well as some of the inconsistencies in views and behaviors. A teacher and a returning resident to Florianópolis after years aboard, she describes the need for doctors to be patient and take the time to investigate what was going on with the patient including one's habits, diet and any deviations from one's regular routine. While she rarely used the system and only for vaccinations or emergencies, she asserted that patients should be somewhat curious and ask what medications and exams were for and seek care as well as be interested and involved in the consultation.

> Sometimes there are people who turn to the doctor for anything, for example, anything. And they do not have the patience, you know? That as soon as the doctor prescribes some medicine … this is what I perceive like when I am waiting for, when I am in the waiting room, I realize that people complain a lot, and do not have patience and already want medicine. So, I think that's it; I think people have to seek more dialogue with the doctor knowing that although he is there, that he is an authority on that subject, he / she has the right to ask, you know? [Patients also can] question why he is talking here with you. But that does not mean I always do that. Many times, I really trust the doctor and if they ask me for the exams, I just go and do it, I do not question why he is asking me. That's it, I guess that's it.

This patient asserts that patients should be involved, but also explains that she does not necessarily question what is being offered or asked for. If she trusts the doctor, the need to question becomes less important or completely nullified. Trust made the patient amenable to the adoption of medical advice and a more passive orientation toward technologies of power when those systems and technologies were perceived as benevolent (Tamar 2014). The nature of SUS as "free" healthcare often contributed to this perception of benevolence.

Most SUS patients included notions of the system and their responsibility to take care of themselves and also not obstruct care, only seeking it when they needed it. Need, however, could be defined by the patient themselves rather than a medical professional and so several patients, like the one cited above who wanted exams and a blood test for her cold, could be frustrated with care. While SUS patients measured their physicians largely by whether they were able to see them and cure them quickly, several mentioned this need to spend time investigating what was

happening with the patient to a larger degree and address what the patient thought they needed. The rapid and one size fits all prescription model was frustrating to some patients, even those who made it clear they felt their care had been exemplary. Some, like the patient quoted below, felt that technology and expediency had created a climate where physicians treated their patients too quickly:

> So sometimes I kind of don't believe the doctors. They attend very quickly. We cannot create a bond with them. We do not feel that they have an interest in solving our problem. They discharge [patients] very fast, give an anti-inflammatory, an antibiotic and in the orthopedic case, physical therapy, ten sessions of physical therapy, but without a diagnosis, without a larger investigation. I'm in disbelief ... from the normal health system ... I think they leave everything up to the machines to discover and then do not know what to do with the results.

The impact that these fast treatments had was a certain discretization of doctors and their expertise. For the patient included above, it seemed to her that doctors did not know what was going on. One SUS doctor cited in the previous chapter also conceded that exams were a way to move patients through the system faster and to avoid having to speak with them, which took more time. The patient above also captures how while some patients expect to be medicated, others feel the prescription is used as a way to discharge patients too quickly without necessarily addressing the root of their health condition and can also lead to questions and a lack of clarity around expertise and the reasons for medical prescriptions.

7.3.2 Rights and responsibilities of physicians according to AM patients

AM patients identified similar concerns and critiques of SUS physicians as their SUS counterparts but often packaged the responsibilities and rights of the doctor and those of the patient in ways that were more explicit and more nuanced than their SUS counterparts and referencing a wider array of behaviors, qualities and practices. The patient quoted below had

spent time abroad using national health care systems in other countries. She highlights education and listening and the disconnect that often forms between doctors and patients when either is missing:

> There is so much that has to change ... because the doctor already comes this way, from a college that I think follows a ... and here most of them in the system are allopaths so then the vision is that everything needs to be very fast, because they have little time to attend many patients with few professionals, right? And there it is, no one listens, nobody hears ... not even the patient can hear very well what that doctor is trying to say and not even the doctor hears what the patient means ... and then, how are you going to help treat that person? I think the problem is the education itself, here in the country. Because then the patient does not know [what the doctor is saying] nor how he will take care of himself if he does not have an education right? And a lot is missing, right? A lot of things...

This patient captures several important aspects of the ideology of AM patients. The first is that doctors need to be able to listen to patients on a level that is beyond the basic clinical interview. The second is that patients need to be able to understand what the doctor is saying and to express their internal realties to the physicians, which requires "education." This AM patient characterizes the typical conventional consult as one of unclear communication and understanding on both sides of the doctor patient relationship and identifies the education and skills required as lacking on both sides as well.

For AM patients, there was an expectation that patients learn how to care for themselves and become empowered by their physicians through this process. Doctors were there to support the human being, not just to treat the disease. Sometimes this meant curing the patient and sometimes this meant helping the patient finish their life on their own terms. One AM patient described this while explaining the qualities of his ideal doctor:

> [The ideal doctor] for me is one that doesn't leave me in pain. I know he cannot perform a miracle, but to find it, to relieve me of pain and give me hope that I could solve that problem. Today I say this, it may be that if I come here at eighty years, eighty, seventy years [of age], perhaps I would say: look, let me follow my course, do not interfere .... I'm going to finish my way around here and not interfere with the process. And why not? Stay three more years for what? I think the ideal doctor is the one who looks first for your illness while also looking at you too. So a doctor who has the sensitivity to perceive what the patient feels, and lives what the patient needs. One obvious thing; he needs to cure the disease ... but it depends. Who

> knows, that disease might not have a cure and anything the doctor will do will only hurt him - the human being, - even more. So I guess it is not ... I do not know if the purpose of medicine is simply to extend the existence, the breathing of the living being, perhaps that is not the ultimate reason. But even so, it has to also be in tune with the patient, with what the patient wants ... there must be other questions.

AM patients like this one tapped into the notion that physicians were there as guides but not necessarily the deciding factors in treatment. Medicine was not just to extend life, and being attentive to patient needs meant also being attentive to the life course or "process" this patient references above. Patients also generally expected consultations to be more dynamic and collaborative. AM patients also discussed wanting doctors to give you their full attention, to know you as a person instead of a disease. They wanted their doctors to be responsive outside of the consult as well and many had their doubts attended to through WhatsApp messages, and house calls.

There was a certain acknowledgement in both SUS and AM patients that doctors were in a difficult position in SUS with the amount of need that doctors had to cope with in addition to concerns over liability. AM patients often cited these factors when they talked about SUS and any critiques they had of the public healthcare system. AM patients often interpreted SUS doctors' prescriptions through the lens of liability and the constraints these physicians were under in order to decide for themselves whether the medication they were being prescribed was necessary or was more of a means of avoiding liability or the patient's return to the health post. One AM patient explained that it was important for patients to have a certain degree of health literacy or medical understanding in order to know what one really needed versus what the doctor felt they had to prescribe regardless of need. Managing doctors and interpreting their intentions was part of the nexus of responsibility and rights between doctors and patients that was constantly produced and reproduced in the narratives and healthcare seeking strategies of patients and also of SUS providers who explicitly discussed the need to manage their patients.

For AM patients, biomedical expertise was filtered through the patient's individual knowledge and experiences in order to weigh what was the appropriate course of action to take regardless of what was prescribed. This pattern did not disappear in AM consultations although since AM physicians worked with patients in a more collaborative way that made negotiation more explicit in the consult, they were more likely to find common ground.

Deciding what one should take for themselves was part of the AM pattern of care. AM patients wanted care to be collaborative. (While this is also a narrative present in Waldorf education, only two of the AM patients I spoke with had been Waldorf students.) AM physicians also operated from this role of looking into the life context in order to provide appropriate care. One physician quoted William Osler who said "*Listen to the patient; he is telling you the diagnosis. Listen longer and he is telling you the therapy.*" The success of the consult was deeply staked in exchange and in acknowledging the expertise and individuality of both doctor and patient. When describing the doctor patient relationship this patient referenced how self-knowledge was integral to accessing medical expertise responsibly. She had recently changed professions and frequently mentioned the need for reflection. She also had a long standing interest in the PICs including floral therapy and stressed that health required a certain degree of self-knowledge:

> Poor doctors, they also suffer. But I think a good patient is one that knows themselves, because it gets complicated for the doctor. I think you need both of them, right? The two need ... the person, the knowledge of both patient and doctor. I think you need half-half like that. Then one also needs to know oneself. Because there are people who have a headache and do not know why they have a headache. It's absurd that .... it's absurd. So of course you know why you have a headache. So the observation, of the person – of oneself - she will know what it is ... unless, of course, something really appears like a virus or something like that. But the person will know: - no, this here is not alright... no, this headache is because of this or that. So I think in my opinion it would help. Now I do not know if another person, another doctor prefers that the patient knows nothing and then he [the doctor] solves everything ((laughs)). But I think I prefer it to be collaborative if I were a patient, right? The way I'm here, I'm talking about me.

The patient quoted above, while framing her ideal doctor, contextualizes the doctor patient relationship within that frame. She, like many other patients explained the need to recognize the humanity and imperfections of doctors as human beings who were neither perfect nor beyond reproach. The doctor patient relationship required a "half-half" input and a certain degree of self-awareness. Education and mastery of the AM view of the person and health and disease played a significant factor in this issue since in order for a patient to be able to articulate what was wrong, they needed to be in touch with one's own state of being and processes. They also needed to be honest with the doctor about their state of being and perhaps also having a certain degree of medical understanding. Being able to articulate what was going on to the doctor with a degree of subtly meant being able to identify what is wrong or at the very least that something was wrong. This idea largely affected AM patient seeking behavior. Many AM patients arrived with complaints that were not clearly articulated illnesses but rather a feeling of imbalance, of malaise or of being existentially "stuck."

For AM patients, physicians were more than the person one saw when they did not feel well or were sick. Physicians were able to look at your life context and the person in front of them and support patients to take the necessary actions to move themselves through the challenges and lessons of everyday life. AM architypes of the ideal doctor then explicitly or implicitly characterized doctors as almost mystical characters who were awe-inspiring in their ability to hone in on the problem while also being familiar and reassuring like a family friend. AM patients, despite asserting that one should not expect doctors to be super human and be able to cure everything, nearly always named their AM physician when explaining their view of an ideal doctor. They also often likened them to mediums or witches with their mystical skills that enabled them to know what was going on and how to fix it. One patient explained she chose an

AM physician after the physician examined and spoke with her and came to the same conclusion that another doctor (her brother) needed to run blood work and x-rays to find and diagnose when she had sought a second opinion. The AM doctor had examined her physically and spoken with her and without labs had diagnosed the issues "written on her body."

The almost magic like quality patients attributed to their AM physicians and the consistency with which AM physicians correctly diagnosed and successfully treated patients inspired considerable confidence and trust that physicians were both competent and invested in their patient's well-being. Sometimes this meant helping the patient help themselves in sorting out challenges in their own lives that were manifesting as illness. Physicians often provided perspective and one that was captured in their written notes about the patients that could span years. Physicians revisited these notes before they saw their patients and sometimes revisited them with patients to give some perspective on the trajectory of the patient over the years. As one patient put it, physicians were there to "*keep my feet on the ground and on the right path*." Ideal doctors were guides to clarify the moment in time a patient was living in, contextualize the problem within this and listen. She explained this as:

> I think the doctor has to not just listen, [but] have to be willing to listen and have this perception of what is beyond what I am talking about, what is being shown by my body. Maybe this way, through this sensibility or the care the doctor is able to show me the paths and lead me to questions that maybe haven't been realized. They need to be delicate in their care, right? But show me also, be firm like this, show me, make clear to me the situation to take charge of, to be aware of the situation and do the necessary treatment. He is a doctor who knows a little of my life, thus, not only of the problem that I am bringing. He knows my story. So, one thing I think is pretty incredible, at least in my consult, is this question of bringing the biography like this ..... I think it's very cool. Because you only realize things yourself in that survey there of your life. Then there are things there that are revealing as well.

Listening extended far beyond what one might think of as "talk therapy." It had to do with the kind of medical gaze patients experienced and the kind of socio-medical space they were in that AM physicians created. This gaze contrasted the gazes most AM patient's

referenced from the SUS experiences. The biomedicalization of life that has made SUS both necessary and taxed expanded the ability to shape cultural norms, notions of identity, entitlements and responsibility. AM patients typically distrusted this power and reinterpreted risk and responsibility in ways that countered the embodied social norms in the conventional clinical gaze (Clarke, et al. 2010; Foucault 1963). The production of the modern Brazilian biocitizen that is coproduced by SUS and the nation-states depends on the distribution of a certain kind of knowledge and vision that AM patients often reject or reinterpret. (Fan 2012). Actively participating in SUS makes one subject to its medical gaze and the value assigned to them through this ideological system (Grewal 2005). AM patients circumnavigated this by funneling care through an AM provider with an alternate gaze, approach and set of skills.

AM doctors were often credited with listening to their patients. Listening meant leaving room for patients to participate in this space in ways that were meaningful and important to them. It also meant having the space and assistance to process one's illness in one's complete life context. The ideal doctor was concerned with the whole person and knew the whole person making the patient feel better before they have even been treated. In AM, this supported a doctor patient relationship with a considerable amount of trust – the currency that underpins a great deal of patient's compliance.

One AM patient captured the importance of quite clearly explaining: "*if I'm not confident, I'm not going to take something that someone recommended when they won't even look me in the eye."* She had come to AM through enrolling her children in a Waldorf school and seeking AM care after experiencing a number of chronic issues including thyroid cancer. She was a impressively practical and straight forward in her explanations about what she had looked for from her doctors. Patients , like her, who had time from their doctors provided rich context for

providers through their biographies. It was important for AM patients to feel seen as who they were, for their doctors to know who they were and engage with them from this place of knowledge. She went on to explain:

> A good doctor for me is what I found in anthroposophy, a doctor that knows your life story, knows your family; the family doctor is the ideal doctor. They know your biography, your descendants, your ascendants, who knows ... not to simplify the diagnosis but to know how to look at you more broadly for me is the ideal. They have a flexibility and are not so radical, - maybe in anthroposophy sometimes not everyone has such great flexibility, but I think Dr. - is very open to talk about things. But for me it is mainly this ... that it's not restricted to the symptoms, reflects a little more, that it is current with modern medicine, new things ... it is always studying, right? I think the ideal doctor does not stay in one spot in time ... we change and medicine must change ... that's it.

Or as another put it when contrasting AM and SUS providers:

> Allopathic doctors ... no ... I talk to them and they ... do not look me in the eye, some are with the computer in front of them, they fill in the form, they ask the basic questions for example how are you ... or if you have had any surgery, if you are taking any medication, no matter what they say ... there they medicate and do not deepen anything, nothing ... do not explain ... they trust the medication right? I feel like it's such a standardized thing, this medicine puts everyone in the same drawer. The focus on pathology will always keep medicine this way because they do not seek to know lives of their patients, their biography. It [medicine] does not individualize, right? He does not see you as an individuality; he sees you as one more who has that issue there. And as the allopathic remedy it does not address the cause; it addresses the effect. They are going from the disease and not going to the cause; they do not worry about the cause, right? And also before the cause, which I think is out there ... before. What made the person ... what he calls ... "*somatizar*" right? That issue.

The second patient was the typical male patient in SUS – only seeking care when in agony or grave dander. Yet in Am, he was a regular visitor (every three months for checkups) and a staunch objector to allopathic medication. In his response he links somatic individuality to responsible personhood and the for the doctor to consider the life context and focus on prevention. While this is not based on the impact of genetics in Novas and Rose's work, AM patients do reference a "mutated" personhood that impacts expectations, values and views of responsibility and being a "good" or "bad" doctor or patient (Collier and Ong 2005; Katz and Marshall 2004; Novas and Nikolas Rose 2000). Instead of expecting physicians to combat disease, AM patients expected their AM physicians to help them avoid it, to heal themselves, and

learn from it. They wanted an individualized approach to their care and one that considered the whole person, their history and the current concern together. There was a greater sense of maintenance and reflection as a goal of the consult. One of the youngest AM patient participants in her late twenties expressed this need for an individualized approach and to be listened to. This need had been realized to a large degree when she was first pregnant and was seeking a different kind of care for herself and her child.

> I think [the ideal doctor] is very similar to what I experienced today [at The Clinic]. I think it's like this: that the doctor sees the person in an integrated way, right? And he sees all the facts that occur in a person's life to make a diagnosis taking into account the emotional, psychological etc. I think that's what I searched for in anthroposophy and I found it. This is good … being attentive, knowing how to listen, not to medicate for every which thing. Sometimes people need to change their lifestyle. Sometimes it is not a remedy that people need; they need to change their lifestyle, work less, change their city, do physical exercise or what not. I do not think everything is medicable, right? You need to meditate ... I do not know, right? Find peace, I do not know. If I separate, I find a new love; and then I think the doctor takes all of this into consideration - that he does not think everything is medicine. That, to me, is the ideal doctor for sure. It is the doctor who seeks prevention and not only combatting the thing, because I think that the main role of medicine is getting lost in traditional [conventional] medicine. Because now the focus is only on combat; it is not on prevention. The prevention has to do with emotional, social, psychological well-being and I think the doctor who takes that aspect into account is practicing his profession well.

This patient's descriptions align with the resistance to medicalization, the consideration of the full life context and care informed by that context. AM physicians often found ways to treat patients without medicating them at all, which also made their approach more attractive to patients who distrusted allopathic medication. Treatment plans might be art therapy for example or finding an activity that got a patient out of the house or simply enforcing a routine.

AM patients were very consistent that their ideal doctors were their AM doctors and that these physicians needed to be born to the profession and called to helping people. The ideal doctor was born for that work*: it's the guy who was born to be a doctor, not to make money and talk about being a doctor, that is the worst. It has to be something that comes from ... comes to Earth with this mission to really help, not only to make money ... if I were a doctor I would be this, understood?* While AM patients often asserted they believed their SUS physicians did their

best especially given the constraints and challenges they faced offering care to all Brazilians, they found something in AM they could not find in SUS. This key element was a sense of co-responsibility inextricably tied the expectations of doctors and patients that were linked together. There were very strong sentiments about what a patient was responsible for that overlapped with some elements of SUS assertions of patient rights and responsibilities. Yet, AM patients continued to stand out in how they applied a logic of responsibility and of ownership of power and of authority.

One AM patient who nearly ran the interview demanding each new question when she finished her thought, highlights the repeating emphasis AM patients and physicians placed on collaboration. While her friend, who attended the interview, joked she answered with "German" precision, her response below about the doctor patient relationship is both thorough and somewhat poetic:

> The doctor should "walk with you." He does not impose himself; he is a partner and considers the one who sought him a partner. They must make their way together with mutual respect and reverence. Because in Brazil, especially, I do not know what it's like in the United States, the vast majority of the population places the doctor as a very sovereign authority. Here in Brazil there is a ... the doctor is the one who knows everything, decides everything; he is sovereign. And the ideal doctor is a partner. He guides, suggests, explains and goes forward if he has confidence of the one who sought him out. The ideal patient is also rare. He has confidence in himself, not to give himself unconditionally to the care of another; he decides together; he is co-responsible; he talks to the ideal doctor and helps him [the doctor] to help him [the patient]. The ideal patient helps the professional in any way he can; he helps the professional to help him. He creates goodwill in the professional to be also heard with respect, with consideration. The ideal patient is the author of his illness and his cure. He is the author and has the help of the medical professional and other professionals, not only doctor. Other professionals and other things, art ... his life, nature, it's not just the doctor who can help you, that's what I mean. That's it?

This patient adeptly captures AM patient expectations for doctors and patients encapsulated by a dynamic of partnership and mutual respect. AM patients greatly valued their physicians and emphasized the importance of following medical advice yet they did not place physicians above themselves in the social hierarchy. Patients were "the authors of his/her illness and his/her cure."

The ideal doctor knew how to partner with the patient but the process was not completed without an equal contribution from the patient.

7.3.3 Rights and responsibilities of patients according to SUS patients

In a pluralistic medical landscape, healthcare systems can be attached to struggles over sovereignty, "development" and their particular ideologies that are potentially in opposition to one another. While AM and SUS shared biomedicine as a foundational practice, their view of the patient and of health and disease – and the rights and responsibilities encapsulated in both - positioned the two modalities in contradiction to one another despite aligning on many of the services provided or tools used. Both practices, however, are influenced by the way biomedical practice links itself to notions of individualism and ideals of freedom and autonomy making the body and a healthcare system an important site for the enforcement of self-regulation and techniques and for discipline and care of the self (Foucault, 1991; Gordon, 1998). It also makes healthcare an intuitive stage for claiming rights and designating certain behaviors morally good (Bashford 2006; Gordon 1998; Greco 2004; Metzl and Kirkland 2010; Morgan and Roberts 2012). SUS and AM patients often claimed rights and employed self-regulation and discipline differently as illustrated and their views of "good" or "bad" patients and behavior.

SUS and AM patients often joked when they were asked about the qualities of "good patients" that they were "bad patients." SUS patients for example gave a relatively consistent list of qualities that "ideal" patients exhibited while also explaining that they did not always follow "the rules." One informant went as far to put her aunt's address as her own in order to use a particular health post and a nurse there. She viewed the nurse as "the boss" and spoke highly of the care there although she admitted to not taking the medications they prescribed. While she

recognized this was a violation of the rules. Her "*jeitinho*" or "little way around" was a means of obtaining the best possible care – a viewpoint not unlike AM patients who were also trying to find the best care possible and exercise their right to care through their own forms of negotiation (Katon and Kleinman 1981). For AM patients, this did not take the form of faking their address but it did involve saving money for AM visits, strategically using various medical resources and learning a great deal of self-care from AM physicians for future illnesses. As the patient who put her aunt's address down put it: "*the people in Brazil find a way*."

SUS patients generally characterized good patient behavior and qualities in the mode of service delivery and how one should behave in the medical social space. Good patients needed to have "good sense" and not expect to be seen if the health post was full or if people with more grave conditions skipped others in line. Good patients were characterized as polite and did what they were told. Patients should facilitate the flow through the health post and not obstruct it with their own demands if those demands are not emergencies. This was reflected for example with the SUS patient cited earlier in this chapter who decided not to bother the SUS physician with renewing her birth control prescription since he had seen her promptly for one health concern already. She declined further assistance feeling that it would have been an imposition even though he had inquired about additional concerns.

Patients very clearly identified their own behavior within the system as good or bad particularly around adherence. SUS patients reported their non-compliant behavior as being "bad" patients whereas AM patients often cast rebellious behavior as responsible choices. One SUS patient explained there was a difference between the rights and responsibilities and the qualification of a good patient in SUS and in an integrative health framework:

> [In SUS] I'm not a good patient. Why? I do not take the medicines they send me; I'm rebellious, so to speak, because being a professor, I've always wanted to know a lot about "why" and if they do not explain it to me directly … if they do not convince me that I should do that, I do not.
>
> In integrative health, the requirements of patients are different. A good patient would be one who recognizes what he should do for his health to improve, and he is an agent of his recovery, right? He understands that it will not be good to just take the medicines there, that, that pain can come back if he does not change his behavior and do the things he really needs to do ... he has to want to heal. Patients should seek medical attention as soon as they feel poorly rather than waiting. They should do preventative care even if they have to wait for it.

While integrative care also exists in SUS, this SUS patient makes an important distinction in the rights, responsibilities and expectations of patients depending on which modality they are participating in. He captures the fact that integrative patients expect and are expected to participate to a different degree and are also supposed to see assistance and be actively engaged. His description of good or bad patient behavior in SUS implies asking questions and not taking the medications are associated with "bad patients." Despite describing why, he is a "bad" patient, he does not cast his behavior as responsible so much as an idiosyncrasy that stems from his academic training.

A clear expectation of SUS patients was one of obedience. When SUS patients asked many questions, or did not follow their protocols, they acknowledged this was "bad" even when explaining their rationalizations as to why they did not take the medications. Their descriptions of patients often reflected a deference to SUS limitations and rules. As one patient put it:

> Yeah, it's hard there. I think the patient also has to be understanding, in certain things. In particular, I think you have to respect the doctor, to know that you are not his only patient, both privately and publicly, right? It is, to understand that he is not God, right? He's a human being that can make a mistake, you know. He can be wrong. [Being a good patient] is to understand that the doctor does not need to know everything, like any professional? And [good patients] often have patience too.

Another patient captured the role of patient attitudes and understanding of limitations of doctors as:

> I think the ideal patient would be a person who has to have the will to live, a person who always strives, who helps the work of the professional. No, not a pessimistic person, who thinks that the professional has to solve everything, the doctor. Well the opposite so, people who have a ... who are grateful to be alive. I

> find that being that kind of patient, it helps a lot; it helps all the people around, as well. I do not think anyone likes to be around someone who is depressed, someone who complains, someone who thinks they know. The poor melancholic. No one, nobody supports such a person. Neither a doctor, nor the caregivers, nor the relatives. So I think the ideal patient is that person who wants to live and who, despite having several difficulties -health problems - has hope and wants to improve a lot. This does help you and those around you trying to give you support.

The narrative above captures the expectations of patients to be optimistic, helpful, cooperative and invested in their health. Being anything else was cast as being burdensome to the system. Most SUS patients explicitly tied being a "good patient" to not obstructing the system if not avoiding getting sick altogether. This meant that some SUS patients thought good patients should seek preventative care more often to avoid serious illness while others asserted that urgent need was more important and patients used the system too much:

> The ideal patient is the one who does the treatment correctly and does the preventative treatment for disease too – right now already … is already there doing the tests and seeking, let's say, to not get sick. They go exercise, and have good nutrition. We are prone to relapse right. I think the patient has to do that job, at least try to do that work of eating better, of exercising, which is what they are asking for there [at the health post]. To do the prevention of the disease, [a good patient] always goes to the doctor, does the preventives that have to be done, especially the women --you have the cancer preventives for diseases, right? Today we have a very big problem, which are heart problems because we eat a lot of fat, we eat badly, everything we've talked about, right. So, I guess that's it. I think that doing prevention today was the best way, right, I think the government has to have a project, you know, that the person is going to go ahead and not have to spend so much to do prevention. I've done this treatment before and everyone should do it, you know? The health post in your community has to have this project where you do preventative care so that at sixty, seventy years of age you do not have so many diseases.

This patient captures several important aspects of the disciplining of SUS patients by the health system. Prevention in order to remain well and not burden the system – a public resource - is one. The patient does preventative care and believes others should as well – a community responsibility to access the services that your community health post providers. Similarly, another SUS patient, explained that "bad" patients were those that did not take advantage of the services that the municipality provided. Preventative services are encouraged and considered responsible behavior. Accessing services beyond prevention inappropriately or too often can be

considered burdensome and "bad" behavior. An example of this was one patient who complained about people not going to get free vaccines or free contraceptive care citing laziness and poor education as the culprits. He came from a neighboring city, which also has similar SUS quality and infrastructure. Unmarried, and somewhat of a rakish character, he oscillated between being friendly and offensive, often unabashed in his distaste for those who used SUS "incorrectly"

> It's free for you to take and people do not go even for contraceptives. It's at the health clinic for free for people to take, but they do not go. And that's why there is this large population in *communidades.* A girl has three or four children. And you cannot say they can only have one, right? And you think it's because they do not want to take birth control. It's not lack of information, just laziness, pure laziness and sloppiness, relaxed. They [women] have many options here. There are several options they give at the health post, several options. Besides the contraceptive, they put in IUDs; they put a lot of things. Women can have that injection. Everything is free. Once you get pregnant, there is nothing else to do. There's nothing else to do. And then you have one more victim.

The SUS patient here very strongly expresses negative views of people who do not use free services particularly people who are from low-income areas – a population that is also often associated with SUS patients. This narrative reflects similar patterns in Brigg's work where the rhetoric of control and the reproduction of "third world" threats are expressed in medical terms as well as patient risks and behaviors (Briggs 2002). One should note that abortion in Brazil is illegal and men are held financially accountable for any children that are proven to be theirs by a paternity test. This fact likely added to his rancor about not using contraception if it is available. He also lays the blame and agency for procuring contraception solely with women rather than men.

SUS patients characterized other forms of poor patient behavior as being argumentative, late, not taking their medication or not taking them in the right dosages. Medication was where most SUS patients identified the source of their "rebellious" behavior. Several SUS patients simply did not take their medications as prescribed or at all and joked that while they were bad patients, they were also "little researchers." Medication non-compliance was

a way that SUS patients participated in the system but still exerted their agency. Some asked pharmacists for their advice as well using their feedback as a way to assess whether they should take the medication or not and how. This dynamic suggested some distrust or lack of clarity around medication in general. Some of the mistrust occurred when doctors did not explain what the medications were for or how they worked, side effects etc. Still, only two SUS patients complained about the thoroughness of the explanations provided by their SUS doctors. While they had their reasons for not taking medication and explained them, they still asserted that "bad" patients expected too much of their doctors. Non-complaint patients also needed to be disciplined in their behavior and deferential to medical authority regardless of any objections they might be harboring:

> What a doctor does not like is when she tells patients to take medicine and the patient does not take it. The doctor did not like that because she told me to take antidepressants and I did not take them and she was kind of like [makes an angry face] that with me, you know? Said ah no you cannot have stopped the remedy. It was kind of like that, right? She scolded me, and I was like this right [cowering]. Ah, but then I thought she was right. Wow, she told me to take the medicine and I did not take it so I have to accept that I'm wrong and she's right.

While the patient did not take this medication for a reason, she states that because she is the patient, she has to accept that the doctor is right and that she is wrong. I was somewhat taken aback when this middle-aged woman mimed cowering like a child under the frustrated gaze of the physician during our interview and her assertion that she had to accept what the physician had prescribed. This delineates a very different kind of balance of power than one finds with AM doctors and their patients. In SUS, this element of being disciplined and deferring to medical authority could also be seen in how patients moved through healthcare spaces so much so that the following patient did not even sit down when her doctor overlooked asking her to do so when she came in with her teenage son who had been hit by a car:

> And in the hospital when I took him myself, I realized that the doctor, he went into the office to get a pen, but at no time did he ask who the patient was. He did not say to me that he was going to treat my son. In fact, he did not invite me to come in, and my son was a minor. At no time did he ask about our relationship, did not ask him how old he was, nothing. Maybe he had files on the computer. I do not know, but he did not ask, and he did not ask who was the person responsible for him [her son], although [name] is sixteen but he was younger. And he did not invite my son to sit down. There were two chairs in front of him. My son and I stood. He attended us in five minutes, looked at the exam, and we are just standing there. I find that unacceptable. Both in private and in public care.

This patient clearly had expectations for what the doctor should have done particularly in regards to the ritual of the appointment. While the doctor likely had the relevant information on file, she had no way of knowing what the doctor knew and did not know about her son. Here, the computer is a repository of information for the physician but remains a foreign and inaccessible object to the patient's mother who has no way of knowing what information is and is not there. She went on to explain that her son, who had been hit by a car, was not even so much physically examined by the doctor. He did not look under his shirt to examine him but sent him for x-rays and prescribed pain killers. Even her son said "*why would they call me back to see the doctor if he isn't even going to look at me*?" While she attributed this treatment to the fact that it was the emergency room and there were a number of cases that made theirs look banal, she was appalled by the treatment but she nevertheless did not feel she could sit without permission or assert who she was or what she felt entitled to for herself or her son. This instance illustrates the kind of discipline of bodies and exertion of power that patients internalize and reproduce inside and outside of the SUS medical setting (Foucault 2003; Genel 2006).

SUS patients clearly expressed the need to defer to medical authority and be cooperative even if they did not always do so themselves. Doing what one was told, being patient and engaging with preventative care to minimize the need to use curative care were all regularly stressed as the responsibility of patients. By right, patients had these services available to them but using them "correctly" and avoiding illness was their responsibility as patients. The shift here

of individualizing responsibility and risk has important implications for how patients personhood is being imagined and managed (Braun 2007; Harwood 2008; Possmai-Inesedy and Cochraine 2013; Tamar 2014).

7.3.4 Rights and responsibilities of patients according to AM patients

For AM patients, there were a number of overlapping characterizations of good and bad patient behavior with SUS patients. Patients in both modalities emphasized that the importance of following the health plans, being understanding of the limitations of their doctor and to be patient. AM patients heavily emphasized the need for honesty in all aspects of the consult including the events that led up to the health condition, the health condition itself, whether they were following the health plan and if the health plan was working or not. AM patients also emphasized the need to work with doctors as well as the need to reflect on what lead up to the health condition itself:

> The ideal patient is not impatient, right? A patient who is not patient is difficult ... but the ideal patient I think comes open to knowing, to not want someone to have the answers for everything. [To not expect] a magic prescription that will cure you ... a person that will be open to transformation … a person who does not want something but who accepts the processes, who wants to understand ... [to understand] what age you are in life and can understand the situations that you have to experience in your life now rather than later. If things are not good, he [the patient] says something because if not, then he has to return [to the doctor] and say things [the treatment] did not work … he does this so he does not remain a patient. It's not that the doctor did not choose the right treatment, … the doctor does not know it did not work because the person never returned to tell him sincerely what is good and what was not good in order to try to find another path.

Here the AM patient references the need to be honest with physicians about what is going not only with illness but also with the process of treatment. The patient should come to the consult with openness to discovering what is going on as well as a certain degree of reflection on the process and oneself. Anthroposophy thinks of the life course of individuals in 7 year blocks that

correspond to periods of development for the etheric, astral, ego and physical bodies with associated challenges. The patient's reference to "understanding one's age is a reflection of an AM conception and reflective process on one's own biography. Understanding what "Age" one is living is also understanding what aspects of yourself are in development and a way of contextualizing challenges of the life course. An example of lay conceptions of life course challenges that have some equivalency are adolescence or the midlife crisis.

Part of being open and reflective in consults (and potentially between them as well) is the search for balance. AM patients frequently used words like "seek" "balance" "equilibrium" and "questions" that were all tied into the biography and destiny of patients. Health was something to be sought rather than delivered. Health was far more akin to "*salutogenesis*" rather than an absence of pathology. "*The good patient is someone who is open to looking for equilibrium, who searches for health, who has to be open to the truth, and to be honest with what they are bringing. They have to be confident in the doctor and open to following their orientations."* For AM patients, their honest self-reflection and truthful articulation of this reflection was highly valued. Their narratives were interwoven with the quest to be and articulate one's authentic self, to take responsibility for the present and strive toward a more balanced future in ways that were often explicitly stated. One middle aged male patient who rarely left his farm in a rural area, save to see his "friend the doctor" at The Clinic stated this saying:

> I think the ideal patient has to look for the best [thing] for him, right? You have to seek your freedom, in the clear sense, always respecting the other, but seek the path and try to meditate like this and try to listen to yourself and try to find your way. I think the ideal patient has to do this. We know it's an exercise ... it's an exercise ... but that's it ... that's what I think. You have to search for your way, try to have the sensitivity to know what you have to do here.

Other patients used phrases like "having to find what's best for himself/herself" and ceaselessly striving towards this goal or destiny. Medicine was not so much to treat a condition but to help

the patient on their path and therefore address illness. Illness was not so much the collision of organisms with biological agents or conditions, it was purposeful and merited reflection and required attention and intension on the part of patients and their doctors.

Along with the existential aspects of "good patient behavior" AM patients had a somewhat different relationship to authority. Like their SUS counterparts, they referenced the need to listen to their doctors, although many AM patients who self-identified as rebellious in SUS reported also listening to those they trusted. AM patients also reported evaluating claims of doctors more and assessing their validity and sincerity more that their SUS counterparts. The ideal patient was one that searched rather than simply deferred to authority. While many AM patients trusted and followed the recommendations of the AM physicians there were also narratives that indicated patients did their own homework and were concerned with getting the best form of care for themselves and their families. They saw themselves as unique and in need of finding their own unique resources and solutions:

> I think the ideal patient is a patient who is an investigative patient, is a questioning patient, who does not accept everything that is imposed on him. So, you go to the traditional [biomedical] doctor and do not accept it all. You always try to find ... I think the ideal patient is one that is looking looking ... you see, I drink in all sources. I'm not a professor; I do not drink only from anthroposophy. I do not only use the anthroposophic remedies ... I go to phytotherapy; I go to normal homeopathy. So, I think it is a patient that finds this balance in various medicines, has several ... there are those who like Chinese medicine, acupuncture ... I think it is he who seeks healing - the ideal patient seeks the cure that best fits him.

One can see how narratives like these provide a certain contrast to SUS narratives surrounding the rights and responsibilities of patients. This patient quite explicitly expresses a certain degree of agency and unapologetic drive for what is best for him. It is the right and the responsibility of the patients here to make the choice of what forms of medicine are best for them and to access them, take their recommendations or reject them. Patients are investigators and challengers to a

status quo that does not take their individuality and personhood into account. AM in many ways is a vehicle for this activity.

AM and SUS patients both had clear assertions about the right to health and accessing services, but they interpreted these mandates differently. Differences were captured in the contrast of patient rights and responsibilities and expectations for their doctors. AM patients distinguished themselves from SUS patients by identifying the need to understand what the moment required, the flexibility to evolve and the independence to take ownership of the illness, interpreting it through a lens that added additional meaning to suffering. Illness was not due to a lack of access for AM patients, it was a lack of understanding and access to what they were seeking. One patient explained that access was not so much the problem as "*Brazilians seek care for an acute symptom and he wants a tablet to solve everything and does not want to change his attitude in relation ... he wants a tablet to solve everything."* While this patient echoes similar complaints by SUS doctors about medicalization, one also has to consider the relatively ability of the "average" non – AM versus. AM patient in their ability to make lifestyle changes.

7.4 CHOICE AND RESISTANCE – ANTHROPOSOPHIC MEDICINE AND THE PRODUCTION OF NON-CONVENTIONAL BRAZILIAN BIOCITIZENS

As seen in Chapter 1, patient choice is typically framed as a hierarchy of resort built around factors such as: cost, access, whether a patient knows someone who likes a particular modality or physician, and how effective the patient believes the treatment to be. AM patient choice violated many of these classic models on choice. AM care was more expensive, less accessible and unadvertised. Many patients had only heard of it through the Waldorf school and sought it out

because they wanted to be viewed as they saw themselves and treated according to this vision. Because SUS was born out of democratic reform and extended the reach of the state into the everyday lives of Brazilians, it has the ability to shape patient's visions of themselves as human beings as well as citizens. AM patients who rejected this vision, represent a minority group challenge to the national culture and narrative encapsulated in SUS as well as a platform for altering the demands of citizens to the state (Aretxaga 2003; Castañeda 2007; Foucault 2003; Genel 2006). AM patients expressed how AM provided a different narrative for and about the human being and their place in the world. While there were some concerns over types of treatment like medications, AM patients typically sought care that aligned with a vision they had of themselves that AM augmented and/or reinforced i.e. the life context shapes the individual and illness and disease.

AM patients, like SUS patients, expressed concerns about the toxicity of allopathic medications. But choosing AM extended far beyond looking for something more "natural" and resisting the cascade of medicalization. The choice of an AM provider was deeply rooted in how patients wanted to be treated and seen by the medical gaze. One AM patient who was in his late forties had calcifications in both his shoulders that made movement painful. His SUS physician had explained that this was likely to flare up at any time and get continually worse with age. As a deeply active person, this explanation had left him terrified and his wife, who was seeing an anthropsophic gynecologist, suggested he see an AM doctor at The Clinic. This physician went through the whole process of x-rays and exams and prescribed certain anthroposophic remedies that are related to the structure of the body - specifically carbon. The idea that carbon and the body were similar and shared a certain structure resonated with the patient who was able to align the medical reasoning with his lived experience. After treatment, he had vastly improved and

showed no calcification in one shoulder and less than 10% in the other. He made it clear that he did not reject biomedicine especially in the value of their diagnostic exams but he wanted to be looked at as a whole first. After being looked at this way and regaining movement in his shoulders that helped him avoid surgery, he was a believer in the AM approach:

> So all this part [the human being] is seen before you go under scalpel [in AM]. I imagine if you work this whole being, this complete set – of you as a human being - I think it it's like "let's look at you first and see what you doing right or not very clearly." Then, if there is no way out, who knows … you go through something a little more invasive. And that [approach] is what's good, that's good.

Beyond the medical gaze, this patient responded to a gradual approach that took his concerns and fears about surgery and future mobility into account. Because of the way the illness and the cure were conceptualized and explained, he was able to align his life context with his illness and health plan in a way that made sense to him. He was looked at as a complete person and had his concerns and doubts attended to. After a thorough review of his exams, his physician took a conservative approach to care reserving surgery as a final option. When that approach was successful the patient had their needs and expectations met.

Choice to be part of AM had much more to do with how patients wanted to interface with physicians and be treated rather than the treatment itself. AM patients still had allopathic exams, procedures and medications when the AM physician called for using these services in tandem but all of this care was routed through an AM physician who was an interpreter of medical language and life context bringing it all together for patients to process with the physician and beyond. AM physicians were there to orient patients and often patients learned to take care of minor maladies like colds, fevers, pains, sleeplessness and so forth on their own.

Unlike SUS patients, AM patients were often looking for integrative treatments for illness experiences that did not fall into neat topologies that are associated with PICs i.e.

acupuncture for migraines or pain for example. AM patients spoke about a need to incorporate what they were living, a moment in time they perceived as important in their evolution and wanted clarification or assistance moving through it. Some patients described these moments as a "maturing" or "ripening of the self." Because AM patients did not always seek care for specific conditions, they often framed health seeking as "*bringing their questions*." They certainly sought care when something was not right but this was not always tied to being sick. One physician explained she was treating a woman with a constitutional remedy for the heart for what could be characterized as "shock" or "heartbreak" after the sudden death of her husband. Sometimes patient concerns were characterized as a general feeling of malaise or noticing an altered state in children who might need assistance to move through a developmental stage. One woman for example, brought her child in when she noticed the child was having some difficulty mastering jumping and biking, which at his age would have been developmentally appropriate. The doctor spoke with the mother and had her son draw a picture and used the drawing as a diagnostic tool to see how the child was "inside" coming to the conclusion that the child needed practice integrating his physical body with his other "bodies." The mother described this consult saying:

> During my son's last consultation, when he was seven years old, we talked about how he was at school, his behavior in the house, in the family, how he is, in relation to life, how he is expressing himself, if he is very anxious, if he is sleeping well, if he is a sad child, a happy child, if he plays - knows how to play ... what his access to electronics is like, his interests. Then we made a drawing and we took a look at this drawing. A physical assessment was made of how he was and then we arrived at a therapeutic course for him. So we made an appointment without an illness; he did not come to treat a sore throat, a flu, nothing. He came to evaluate how he is within the constitution that he presenting. Then we realized that there is something that we can do to help him to adapt better, that there are some difficulties that he is facing and there was a trace ... that was the consultation. Medication and external therapy were prescribed to help him.

Constitution here means something very specific in AM relating to the character of the person. There are four "types" of constitutions in AM: *melancholic, sanguine, choleric and phlegmatic*. Like humoral medicine, these constitutions related to the person's personality, biotype (body

type) and often gait. They are also associated with colors and among other qualities. These four constitutions are also related to age. Children for example, are considered more sanguine by virtue of being children even if they are phlegmatic children. Generally, individuals express a certain type fairly consistently throughout their life although this can change and each person is a mix of the types. These types also tend to indicate what health conditions patients are more or less at risk for. The physician in this case asked questions to assess the child's constitution and whether there had been major changes, as well perhaps as addressing his risk for certain conditions. While this mother did not name any health condition or illness or what treatments/medications were prescribed, they were frequent visitors at the clinic for eurythmy – a form of anthroposophic movement therapy.

Cases, like the one above, called for medication. Most AM patients were resistant to allopathic medication but did not express this same degree of resistance to AM medication. This was due to how they viewed the processes by which these medications worked. AM medications were seen as working with the body's natural processes and forces to help the patient heal themselves. Allopathic medications were considered foreign, synthetic and aggressive or a kind of hijacking of the bodily processes. These bodily processes were tied to the patient's context, constitution and being. To alter processes meant a certain degree of interference in the self and the development of the self. One patient explained that she preferred not to use biomedical products if she did not have to because they did not "improve" the person. Here the patient makes a distinction between what constitutes the body and what constitutes the person. A hijacking of the "vehicle" so-to-speak is an artificial interference in part of the person. One AM patient who came to AM through the Waldorf school and worked in public health explained:

> Because I am from the health area, I think they [allopathic medications] are always anti-physiological, right? But sometimes I need an antibiotic. But to always have the anti-inflammatory, antipyretic, anti-

> everything I think it is not ... in health, I don't see it as a way of improving people and healing. I think healing is another way, more pro than it is against. That's why we prefer, right? Because we believe in the healing forces of the person more than just being against the acute process, right? I have these three children; the boys have never taken antibiotics. If they took anti-pyretics it was very rarely to be able to sleep at least so, if their diseases were not always controlled by themselves ... they were learning to control the things in themselves and I think that medicine goes in that direction, to support their healing forces. {name of child] had to take antibiotics once she had pneumonia, but it was never needed after that. We notice how they grow stronger, as time goes by. Because of this ...

Here one can see how AM patients frame illness as purposive. For children, it may be about mastering and taking ownership of the "physical vehicle" - the body. It may be about needing to change one's ways, style of living, mode of thinking, way of moving through the world. Illness was an opportunity to improve oneself by moving through the lessons and the process that illness comes with. Sometimes patients are not able to overcome illness on their own, however, and interventions like antibiotics are called for like the case of the child having pneumonia. Choosing AM treatment meant coming open to learning these lessons and doing the work as well as being honest, reflective and committed.

7.4.1 AM view of health and disease and the life course

A distinguishing characteristic of AM patients was their disease etiology and the way they framed the illness experience within the greater context of their own lives. It set them apart in their sense of integration in the wider social context of citizenship and created community– a biosociality of joined interest and shared ontology of personhood rather than risk. This allowed them power to form and developing alternative relationships within themselves, the state and society. The power that was initially predicated upon the medicalization of life through SUS and ensuring regulation was reimagined in a different social medical space to create new forms of community, identity and rights (Friedner 2010; Petryna 2004b; Rabinow 1996; Shaw 2012). A

central aspect of this process was the AM vision of the human being and the role of illness in the life course. Patient frequently explicitly stated that disease was purposive and part of one's development as a human being. Some expressed using allopathic medication too frequently as "sabotaging" a disease that one would likely have to live through again in order to resolve the issue that called it into being in the first place. As a whole, AM and SUS patients expressed different conceptions of health, disease and their causes stemming from different understandings of what it means to be human and the role of illness and health and medicine in human development.

AM patients were a notable group of patients looking for treatment that aligned with the view they had of themselves and their illness as well as being able bring this into a consult. One such patient outside of AM was the patient who had had hepatitis B and quit her biomedical treatment referenced earlier in the chapter. She came to view her hepatitis as a lesson and something that added meaning to her life. Her changed attitude not only helped her but helped those around to lead better lives and have better relationships:

> So I'm resuming my treatments at the *Spiritist* Hospital. I've changed my diet again. So, I think it's one, these problems I have, they will not end, they will be cyclical like everything in our lives, it will depend a lot on my, on my emotions, right? And I think there's a very good thing I learned from this disease. It was that it came to teach me a lot and open many doors that would not open if I were healthy. The people I've met, the treatments I've discovered that exist, all these things like that, are very ... are things I've known and are part of my reality today because of this disease. So I do not have to revolt - none of that. There are people who, when they get sick, [they say] "Ah, God did it to me." I do not think so. I'm thinking illness is a reason for me to grow up ... And the interesting thing is that this growth is not just mine. The people in my family, are, who are seeing what I have done, my faith, my improvement, they are also looking for the same treatments. I'm infecting people with it (this approach). This is very good.

While this patient was not an AM patient, she characterized illness very similarly from her own Spiritism context. She, like AM patients, expressed the need to understand the lessons of illness as well as what the illness calls one to do. Patients needed to attentive to the demand signal - to the first warning signs of opening the doors to disease and then to take actions to avoid opening

the door to disease. Disease also came with an opportunity to better oneself and one's life. This woman had improved strained relationships with family members and expressed feeling empowered by taking responsibility for her own care the way she had.

Being responsible for AM patients often took the form of not only being attentive to oneself when they noticed something was off or on its way to becoming imbalanced. Being responsible meant routine maintenance. For this reason, AM patients were much more likely than their SUS counterparts to seek care more regularly. Some patients came every 3-4 months for example while others came for their children's checkups and "checked in" with their doctors or came once a year for example. There was a clear sense that catching the problem before it bloomed into a full-blown illness was "responsible." Sometimes this meant learning necessary lessons before illness made you learn them. One dramatic example of this was a patient who was forty-seven and had not taken allopathic medication since he was 7 and reported never getting sick. He attributed this to taking care of himself and paying attention to what he interpreted as warning signs:

> It's like this: if you only drink water when you thirsty … you have to drink water all day to not say "ah, I'm dying of thirst now," understand? If you're dying of thirst, you're already dehydrated; you're losing water; it's not good. You have to drink water all day. My wife and I always [come to The Clinic] with our daughter. The doctor's interview always asks a question, how is she [his daughter], if she behaves and we will ... because I believe that everything like this – signs. For example, if the girl is very agitated, she already has a signal, there she has ... "Oh, there's something to settle here." If you leave this [unchecked], later it can become a thing where you may have an illness. I do not believe in sickness; I believe in the sick. The person creates the disease; I do not believe that you have diseases like this ... you open the door for you to become sick, understand? I believe that we create everything, cancer, we create it ourselves. I do not believe in anything that has the thing that comes from outside to inside. It is yourself that has the mental -- the thought makes everything. That's why I sought anthroposophy just because of it. With certainty we will all have a "bag" like this, a bag to open, there is something inside ... then I think that anthroposophy is helping you to go, to stay as a human being, not like just one more person ... with traditional [conventional] medicine you are one more, who is another, who is another ... but each one is different right? Each one has a mission, so that's it right? If you ignore this ... you're not moving forward. And that's it, understand?

There are several aspects of this narrative that are characteristic of AM patients in particular: disease as purposive, the need for preventative and attentive care to a lurking demand that can

bloom into illness, and the aspect of becoming a human being on a unique path. Ignoring this path - this mission - is grounds for not evolving or "moving forward" and of perhaps creating the need for illness in order to course correct. The "bag" references was used in anthroposophy sometimes as a way of describing the karmic "backpack" that an individual incarnated with. This included one's challenges as well their capabilities and destiny. Other AM patients echoed the idea of a unique path and destiny regularly. These two patients for example are just a few of the iterations of AM disease etiology and ontology of personhood:

> That healing is a process, right? So we go to the doctor not necessarily because we are sick, but because we need to improve in some aspect, right? And we need to be better than we are sometimes, more support to go through the circumstances of changes, the phases that we go through, every now and then we go through some phases, like the one I went through. I am not sick, but due to a change, due to a moment, an emotional crisis, I may become ill, be sick in the future if I do not take care of myself. So the ideal patient is the one who understands ... right? That disease is when it has reached its peak, right? And we can be a patient who is not necessarily sick, we can be a patient who takes care to prevent the disease.

> I think the people, that humanity is going down a path that in my point of view is not right. It seems that anthroposophy cares about the human being and is concerned with preventing diseases and not wanting to sell medicine or sell exams, which is happening nowadays. Even forbidding that anthroposophy can sell their medicines, in fact, so much interference from them, because it is not in their [SUS?] interest, because they want to sell medicines and .... and exams.

Both patients link AM with the path of the human being – with destiny and health. They both call attention to prevention and navigating the path forward as patients. AM patients often fore fronted disease as a function of their life context, which is perhaps what made them generally more amenable to and interested in life style changes rather than allopathic interventions that used surgery or medication. Understanding a patient's life context meant taking into account the lives of those that shared "context" with the patient such as family members. Family doctors were often valued by AM and SUS physicians because they had insight into the whole "unit" and what was going on with each patient and how the patient's relationships were impacting each patient respectively.

AM doctors often worked parents into a child's consult informally although occasionally they added a whole additional appointment in order to work with the full life context and actors

in that patient's life. One patient who was bringing her baby in for her checkups explained that attending to the child often meant also attending to the mother's needs, doubts and anxieties. Visits for the baby often became joint consults for the parents – a pattern that was nearly always repeated with parents of young children. If parents came in for their own consults, physicians also asked about their children – an aspect of the life context of the parent that had tremendous impact on their quality of life. If their child was not sleeping for example, the parents were likely not getting any rest either. This patient with her child described this consult as detective work with the life process and illness. Having the support and care was reassuring to parents and something they greatly appreciated. Having these narratives and consults documented over time, also added a sense of clarity. These records went beyond taking a medical history, they were a part of the patient's history, their questions, doubts and hopes.

The role of patient biography was important in AM not only because it allowed patients to be contextualized fully outside of their illness, but also because it gave providers and patients a chronology that could be revisited and reflected upon providing perspective on the life course itself. One patient cited her physicians work with the biography as a reason she thought her AM doctor was the ideal doctor:

> The ideal doctor is very close to what Dr. [name] does, because she looks at the whole. She does not focus exclusively on the physical body, so I think this is the ideal doctor, who can understand the human being on the four levels and looks at his biography, tries to understand what was the patient's life history to understand why he is there, sitting there with that question. It's a lot Dr. [name] does, so I think my ideal doctor is this, an anthroposophic doctor who has a special gaze at biography, who understands biography as a possible cause or events that cause questions.

The ideal doctor here is one that understands the life course of the patient and how the life course contributes to health and illness. The ideal doctor is also one that understand and treats the patients in a way that aligns with the patient's view of their own personhood. AM physicians in some ways are like patient historians in the sense that they both solicit lifeworld narratives that

incorporate the history of their patients beyond the medical history as well as record this history across the years of care. These records are in some way quite precious as they demarcate the journey of the patient, their challenges and their evolution through illness and health and inform the current course of care. It is also integral to patient's feeling seen by their physicians. One physician who moved cities and retired took all her patient records with her to "keep them safe" even if she had not seen some of these patients for years. As this patient, explains the idea of a patient record – physical and otherwise – plays an important role in the therapeutic process:

> I think there is no magic [in AM], but there is a search about what you want to know, who are you ... come on ... you are not just a body right? ((laughs)) Ah, you have a name; there is a story; you have a story. From knowing what you are made up of and linking it to your habits, the chance of success is probably greater than you simply putting the antibiotic on and saying "now it's fixed." This symptom, this disease may return because it [what was treated] was not really what led to the symptom. I think this is a strong benefit of anthroposophy. In my last interview, the doctor checked what was in our first conversation. "What was the first question with you in anthroposophy?" I think it's a very important thing to have ... there you see in that first consultation that you were not only asked what's aching, what's bothering you. You want to know exactly how you got here, right? How did you come? I do not know ... in my case with a man. You can be a woman, you can be a child … and so that story then, in my last consultation with her it was just a little more grief than in that first encounter. It's one more time you have with the doctor that he will know me a little bit more and will check and see if my story is converging with health or not -better health in that sense. I think some physicians within traditional [biomedicine] medicine should also look at this, I believe they should.

The patient here references the biography and the trajectory of the patient, and how the record gives a perspective of this trajectory – a process also illustrated in Mattingly and Garro and Kleinman's work showing the power stories to illuminate otherwise unseen practices and experiences involved in illness and to make sense of experience (Kleinman 1988; Mattingly and Garro 2000). Instead of being a compendium of medical ailments, allergies and test results, it is a collection of the challenges, questions and life course of the patient. This patient also echoes the AM view of health and disease and the need to understand the root cause in context as well as the desire to be seen and treated as a complete person in the medical encounter. Having medicine contextualized in life context made the encounter meaningful especially as these encounters are

linked together over the years aligning, health, illness, life context and life questions through AM care.

7.4.2 Patient care and the AM medical gaze

As many scholars have shown, the intersection of medicine, politics and cultural change provide an important site for understanding how changes are made, received and remade by states and citizens or doctors and patients (Adams 1998; Andaya 2009; Brotherton 2012). The use of a "democracy of health" framework by Brazil's Sanitary Reform movement – still very much present in the narratives of SUS physicians – illustrates how medicine can shape cultural ideology as a symbolic imagination of the State (Brotherton 2012; Bucur 2002; Collier and Ong 2005; Farquhar 1994; Gupta 1992). As such, this framework also informs how patients and doctors view and assign meaning to healthcare choices. SUS physicians who worked with integrative health practices were aware of some of the reasoning behind their patients' choices that went beyond cost, access, perceived efficacy and so forth. In part due to contact with the PNPC, they understood the limitations and benefits of certain forms of integrative medicine as well as biomedicine especially if they had pursued more extensive training in integrative health practices beyond the SUS training. One SUS physician who was well versed in acupuncture explained how he viewed patient's choices and why he had made acupuncture part of his approach to patient care:

> The main motivation of the people who seek the integrative practice is the care in relation to what you are submitting your body to. I think integrative practices, they respect people's time, anxieties and mistrust - people's fears. You are treating or understanding the organism not simply as a machine in which I will give the substance and it will respond to that substance. Integrative practices usually have the least degree of intervention; they work a lot. Let's take the example of medicinal plants. They work with nature. People feel safe when they relate to nature, when they realize that that practice was used millennially, or culturally,

> sometimes it's associated with a grandmother or aunt, so the treatment feels more familiar. Acupuncture, on the other hand, gives a perspective of resolving pain, for example without drugs, or resolving a symptom, a diagnosis without a tougher drug intervention. So it's a little pin that they are putting on my skin, or it's a compression they're doing. People feel they're not undergoing drugs and chemotherapy; they may feel safer. At the same time, integrative practices bring a promise of holistic care, a care that does not make a simplistic association of the biological system and a chemical response. Integrative medicine holds a promise of care that understands the human being as a whole and is not so invasive. Let's think about other practices, practices that work with spirituality or that work with movements, that work with the body. All of them sell it: safety, a more holistic, less invasive therapy and in that sense, I believed I needed to work with this arsenal, with this possibility to intervene without intervening so much. Or to have it as an option.

This physician highlights several important things to consider. He references many of the qualities in integrative medicine that AM patients seek. Naturally there is overlap since AM is a form of integrative medicine. AM, however, has a short history in Brazil and is still relatively unknown outside of its circles. It does not have the same following or name recognition of a practice like homeopathy or acupuncture and it does not have its place in medical schools and residency programs or even widespread inclusion in the public system to the same degree either. For AM patients, choice is in wanting a specific delivery system that integrative health has but that can be rewritten if these practices are coopted. Unlike AM, acupuncture in Brazil is part of a managed pluralism and has been reimagined and reformed in SUS to be compatible with its service – a frequent consequence of aligning integrative practices and biomedicine (Adams 2001; Cant and Sharma 1999; Janes 1995; Janes 1999; Myntti 1988; Wahlberg 2007; Wujastyk and Smith 2008).

AM has a holistic approach to the person that AM patients pursue. They do not use acupuncture in SUS for example because it is still largely dominated by the biomedical paradigm, a paradigm that violates or does not align with AM patient understandings of personhood. Biomedicine does not see their ontology of personhood. It does not treat them according to their personhood. AM patients who are contextualizing illness in terms of a more existential view of personhood, life context and destiny, then pursue their right to healthcare in a

modality where they can access the care that aligns with their understanding of personhood. In this sense, they are non-conventional biocitizens as their rights and responsibilities as biocitizens are different and have in some cases been shaped to be different than their SUS counterparts through participating in AM.

When comparing the health seeking behaviors and views of the rights and responsibilities of patients and doctors of AM patients versus SUS patients, it was clear that AM patients were looking for a different kind of care; it was not about finding a more natural therapy or avoiding being medicated as much as it was about finding care that aligned with their understandings of what it meant to be human, and to be treated according to this vision. Patient individuality and autonomy was emphasized, as was their expectation to be engaged with their treatments and to be reflective on a whole. When explaining why she though patients sought AM care, this AM physician framed her reasoning as follows:

> The Brazilian population is very open to integrative therapies, very open. I don't know if it compares with the American population or the population in Europe; I think Brazilians are more receptive than the majority of counties, right? Because when you say to a Brazilian: this is a "natural treatment", it already makes sense to them. There exists a tradition that comes from the indigenous people, in Brazil, a tradition that is very adept in the use of medicinal plants, and so this fits very well with the population, a population that accepts homeopathy, anthroposophic medicine, acupuncture, phytotherapy … this is very well accepted by many people. Additionally, these medicines are closer to people, right. They are less technical… obviously we (AM doctors) ask for exams, have the wherewithal to do that, but we use significantly less technology than conventional medicine and the fact that we use less technology gives [us] the chance to be closer to the patient. We can listen more to the patient, and so these medicines are closer to the people and so this reinforces this affinity that people have for medicines called "natural" – vital or integrative medicine. So, this is a very Brazilian characteristic – the high acceptance of these methods like homeopathy, herbal medicine, anthroposophy, acupuncture … this is a characteristic of ours, a good acceptance.

This physician mentions several key descriptions of integrative medicine and AM that echo the AM patient descriptions of what drew them to AM care and what AM care offers them. She describes this medicine as "closer to the people" "less technical" using less technology and therefore remaining "closer to the patient" as well as being able to "listen more" to patients.

Despite this physician's assertion that Brazilians were more open to most "natural" forms of healthcare, AM patient participants were far less likely to use other integrative medicine modalities that their SUS counterparts suggesting that the AM patients were attracted less to the "natural" element found in fellow forms of integrative care and more to other aspects specific to AM care.

Working with an AM physician was a choice that enabled patients to have more time with their physician, which raises the question of how that extra time is spent and what does it translate into. AM patients wanted the attention of their physicians, recognition of their personhood beyond the illness and to have the physician work with the person rather than illness. AM used what could be characterized as a strength-based approach to patient care that felt inclusive and empowering to most AM patients. This was reflected in the confidence AM patients expressed in being able to manage their healthcare choices, integrate medical and life choices and trust their physicians. AM patients sought care in both SUS and AM forms. They were also more likely to use AM physicians as their "belly button" for care – a coordinator for interpreting the variety of information from exams, specialists, etc. that patients encountered in the wider medical landscape. AM patients and SUS patients expressed very similar healthcare seeking strategies with less men overall seeking care in both. But where AM notably differed was how patients framed health, disease and the importance of both for being human. AM patients often identified medical questions within a greater framework of existential or life questions: "*It caught my attention because AM accompanied me and my health questions and of my development. Because of this I came to know and arrive in AM. I'm very happy I made this choice."*

Since disease was often described as an "awakening" moment, a way of bringing one's

attention to something they needed to work through for their own development, choosing a provider who could help one meet the challenges of that moment was important. It remained unclear, however, how much of this was present before beginning with an AM provider and how much this was shaped in working with the provider. I would argue that AM providers often developed an existing tendency towards this orientation since most AM patients in their explanations of what they had been looking for were largely in the form of generalities i.e. looking for something "different". AM health consults were often far more than a discussion over health concerns. Patients referenced the bringing of one's "questions" to the consult to work through and reflect on. Being able to do this was an important part of the coproduction of personhood. AM physician provided a structure with which to integrate life context, health and these questions under a kind and ample medical gaze:

> I like [AM doctor's name] consultation because, because she is anthroposophical; she looks at being as a whole; she does not just look at the physical issue only. She looks at physical, etheric questions, astral issues, look at yourself ... then it makes a lot more sense for me to look ... to look for a cause not only looking at the physical but looking at the four bodies ... then the consult for me is a consult in which we navigate these four worlds searching for a possible cause of a symptom that I am experiencing at the moment. It's research we do together. So that's why I like this approach there [at The Clinic] ... And because she is a doctor who has known me for a few years. She already knows my story; she already knows how I am, my questions ... so it helps a lot, she lives my process, she follows my process.

The patient was drawn to AM care because he wanted the doctor to look at his "self," and to navigate and research together. The doctor was able to speak to him in ways that landed even working in his love of surfing into metaphors on health and ways to support healthier choices. This narrative is an example of the cooperative approach to patient care in AM that invites and expects patients to engage with their health and all of the factors that impact health. The four-fold and three-fold view of the human being is a map for patients to make sense of their illness experience and to exercise a certain amount of agency over finding a solution. Coproduction of

personhood also builds the confidence and shared experience of physicians and patients where patients know that their physicians "knows them" or "knows their story."

The patient above contrasted his visit with the AM doctor he described with a visit to his ophthalmologist in SUS. He thoughtfully pondered each question during our interview gently balancing his three-month-old daughter from one giant arm to the other during our interview. While he had nothing but good things to say about his ophthalmologist and generally had kind things to say about everyone he referenced, he also explained he felt there was something missing in his care stemming from his own AM view of the physical body being affected by the other bodies and his own expectations for the doctor patient relationship:

> But it's different because he's not a friend of mine; he's a doctor that I respect a lot, super-respected, super-educated ... a gentleman, really, he's off the chart, great, but he does not know my life story ... he analyzes the physical body, he analyzes my problem physically, right? Sometimes I ask if there is a connection with emotions and such, he ... the answer is: there is nothing proven. I cannot say, cannot affirm anything. And then it's cut off.

The patient believed the ophthalmologist SUS doctor was a high-quality doctor but was still not satisfied because he was not just looking for high quality technical care; he was looking for care that helped him make sense of disease experience within his own context rather than a purely medical one.

AM patients were looking for a different kind of medical gaze that was more humanistic and saw the whole human being (addresses elements of the person that is not addressed or acknowledged by biomedicine). AM patients wanted to be seen by medical gaze that tapped into this idea of the individual path, of a cooperative investigation of the life context into why one has become ill and a sounding board that has the medical expertise to alleviate suffering by addressing root cause and the interpersonal skill to make that investigation a productive and cooperative one. One patient who had come to The Clinic after having a rash the health post

could not cure after three visits, became a believer when her AM physician cured her in two days. She was a regular patient at The Clinic checking in with her doctor every three months or when something presented itself. One day, after her visit, I interviewed her during the lunch hour and she talked explained why she was a regular in AM especially when the cost burden was a concern for her.

> The consult was great. It is a different consultation; it is different from a doctor that when you go you speak, he speaks: - what are you feeling? Then you speak: - I feel this, this and it goes there ((makes sound of writing)) prescribes something. She [the AM doctor] does not do that. She asks about your life, questions about your past, questions about the family, the events in your life. [She asks about] your relationships, friendships, work, because I think they [AM doctors] see, what I said earlier, they see you as a whole right? And everything can influence a disease. For example, I have insomnia. I mean, [I want to know] what's going on, so she listens. I spent two hours in the consultation with her, more than two hours and she just listened and I recounted my story from my birth, the whole thing, my family's story, everything ... understood? Until we arrive and then she has some conclusions. We debate, she debates a diagnosis, she does not say: "Oh, you have it or no, it can be that." Suddenly you can improve it and then the medicines are not exactly for healing, they are for the balance of energies. It's to address what is missing there – what is out of harmony, out of context. So, I find this interesting, because looking at the disease as a focus: - ah, you have a sore throat, right? Why do you have a sore throat? You investigate what is going on, This I find very interesting in anthroposophical medicine. So ... I had a great experience.

Just like the patient who contrasted his visit with the ophthalmologist with his AM doctor, this patient expresses the difference in the structure of the consult as well as the content. She has time and space to share as much of her context as she wants allowing her and the doctor to examine the patterns of her life, illness experience and health concerns. At the conclusion of this narrative she is not told what is wrong so much as the doctor and her explore a diagnosis together. The doctor and patient have an exchange where the patient feels open to challenging any assertions that do not align with her experience while also being responsive to a physician who has taken the time to earnestly hear her out for 2 hours and rather than focus on the illness, focuses on who the patient is as a person – who the patient has presented herself to be.

A significant part of AM care was qualified listening and a medical gaze that was both kind and confident. One patient used to joke AM physicians were like "rocks in the river" unmovable in their steadiness but not obstructing what flowed around them. AM physicians at

The Clinic were skilled in reading the best way to meet their patients. From my space in the waiting room, I saw physicians come down the stairs to greet their patients all day. It was remarkable how they mixed formality with warmth, kindness with firmness, and practicality with compassion. AM physicians left ample time with their patients but they were also quite frank with patients who did not want to do the work. The result was that patients were very clear on what was expected of them as equals in the medical space:

> Well, my ideal doctor, is kind. I have to feel kindness in him. I arrive at the meeting and my [AM} doctors - the two I have - I arrive at the antechamber and I already start to improve - impressive, it happens with them both. According to me, my ideal doctor is the one that when you arrive, you sit with him and he receives you already with that look of kindness. That's it, goodness is the feeling I think disarms you. You disarm yourself to understand the problem. And then he can help you ... because kindness is kindness in the sense of love. I think he wants to help you. For me this is the most important of all.

7.5 CONCLUSION: THE INTERSECTION OF BIOCITIZENSHIP, PERSONHOOD AND CHOICE

When patients say they want a more humanized medicine, they are often referring to a medicine that treats them like a human being according to their understanding or conception of what being a human means or consists of. In biomedicine, there is a tendency to believe that patients who reject biomedical practice reject empirical science – that they do not believe in germ theory or x-rays or chemotherapy. AM patients provide an important example of how patients choosing medical care are not making assessments on whether they think the tools of a medicl modality has value or is true, is cost effective or is even accessible. AM patients were seeking care that allowed them to bring their understanding of personhood to the table by contextualizing and engaging with illness in a paradigm that joined illness experience, personhood, Brazilian biocitizenship and medicine together. While AM patients were more conservative with

allopathic medication, they rarely rejected it altogether. They believed that biomedical exams had value and regularly used SUS in order to obtain them. But what they did with all this information was to route it back through a professional that could include an interpretation of what was going on with the "self" on the backdrop of what might be showing up on someone's x-ray or bloodwork. This strategy allowed them to access and exercise their right to health as Brazilian biocitizens but according to a different interpretation of the personhood underlying the conventional Brazilian biocitizen shaped by SUS. Instead, choices were made in order to align their non-conventional view of personhood with their civil rights as Brazilians. By accessing their right to health outside of SUS and participating in AM's alternate view of personhood, these patients can be understood as non-conventional Brazilian biocitizens with novel conceptions about the rights and responsibilities they have as citizens as well as patients. These novel conceptions underpin their healthcare choices and are also reinforced by their healthcare choices.

The commentary AM patients made on SUS was an indicator for why they chose other forms of care even if they valued the care that SUS offered. When asking what a patient would change about SUS, she replied that she thought the people needed to change. When I asked for clarification she responded: *It's because I think that the human being, he does not know what he has. The poor health system is not to blame. I think that it is the human being that needs to know itself better*. For AM patients, the physical was at best one quarter of the equation in understanding what it meant to be human. For them, physicians who were only working with the physical body were bound to provide incomplete care no matter how dedicated or skilled they were. The humanization of medicine was not just about having more time with patients, it was about knowing how to use that time well – to understand that medication is not always what

solves the problem and to see the patient, understand their experience and treat them according to this vision.

AM patients and physicians acknowledged that AM was not for everyone. For those who expected the doctor to fix everything without any effort or change, physicians often kindly referred out of AM to trusted biomedical colleagues. Patients acknowledged this repeatedly in their descriptions of the responsibilities of patients to show up, do the work, and be honest about the course of events. This patient felt very strongly about AM's value for one's own development as well as the importance of coming to the consult ready to work. Tangled in his two children who alternated running in and out of The Clinic to the garden he explained:

> The patient, for me, he has to be prepared and he has to want it too, because if he goes to the doctor to take a medicine like that ... the patient in that case will not even teach the doctor. Sometimes the doctor needs to learn from the patient, right? If I go to a doctor, I'll sit in front of him, maybe I'll teach him a lesson, but he will not want to see it because he's a doctor; he thinks he studied and I didn't, he thinks: he [the patient] does not know; he did not study. But I studied something else, like experience ... then the patient has to be like this, a guy who wants to move beyond the basics. Because people go to the doctor thinking that the doctor who will save his life, they think like this: - ah, I go to the doctor who will save me. This is rooted in people, ah I go to the doctor and he surely will save my life; it will anesthetize you a little and you'll think it's alright. That's why anthroposophy is not for everyone either, you know? Who is in the anthroposophy? I think that is already a step ahead, you understand, in the consciousness of the thing … of wanting to improve the human being and to be well right? So that's why I hope for my daughter and my son that this here will also pass on ... I've planted the seed and then it will grow here.

For this patient, AM is more than a medical visit, it is a way of seeing oneself and the world and taking responsibility for oneself. He does not want to be rescued nor does he expect to be. He wants to improve as a human being and to pass this seeking and this attitude on to his children.

AM patients were cognizant of the right to health in Brazil and were very active in the way they chose to exercise their claims to it. Part of being a responsible person and citizen was seeking care that was health supporting for that particular individual's needs– that acknowledged their personhood and allowed them to exercise their rights as biocitizens. One patient captured this in our interview saying:

> It is a wish of mine, I think it is important, yes, I wish one day that is not too far off..., that it be soon, that we all have the right to health. That it is something as natural as everything ... that we need a doctor and have a doctor and are attended to. Health should be a priority of the citizen, for the future ... for a near future, right? Because there I think a great cure starts in every sense. If the human being, if the citizen feels protected, if he feels helped and safe at the health level, he will be more present at work; he will be happier; he will be more balanced and I think this is positive for a country like ours, for everyone. I think it will be very good. May those that govern be aware of this.

Ultimately, AM patients are participating in the promise of the right to health in the 1988 constitution. They have taken the rights of the conventional Brazilian biocitizen – forged in the joining of democratic agreements between citizens and states and the interpretation of the citizen through nationalized biomedical care, and reinterpreted those rights and responsibilities of citizenship according to a different view of personhood. This view of personhood expands the ideal of self from the corporeal to the supersensible, of disease from infection to meaningful life question, of illness experience into evolution, and seeking of medical care as an assertion and co-production of personhood and meaning. It is a testament to the power of medicine to shape one's understanding of self, as well as the role of the view of self or personhood on the choice to participate in medicine, what that participation looks like and exactly who the participation is with. Expectations for rights and responsibilities and choice are deeply steeped in this understanding of personhood and how self is allowed and expected to interface or be acknowledged and included in the medical landscape.

8.0 CHAPTER 6: CONCLUSIONS AND FUTURE DIRECTIONS

By re-conceptualizing the role of personhood in choice in a pluralistic medical landscape, this research has shown how medicine can form new relationships between citizens and the state through an ontology of personhood encapsulated in SUS or AM. Democratic reform and the health policies that contributed to it, assumed the conventional Brazilian biocitizen before the citizen took shape. By reinserting biocitizenship into medical pluralism through the lens of personhood and choice, this research shows how Brazilian biocitizenship and the rights and responsibilities therein can be resisted, negotiated and reimagined by participating in other medical modalities that offer their own ontologies of personhood. AM provides such a case through a medical paradigm that has an explicitly different ontology of personhood than SUS despite the fact that biomedicine is foundational to both AM and SUS practice.

8.1 ANTHROPOSOPHIC MEDICINE AND ENGAGEMENT WITH THE PATIENT LIFEWORLD

AM's ontology of personhood is explicitly reflected in their medical training, views of the person, disease etiology and approach to patient care. Personhood is operationalized in AM practice quite visibly in their engagement with patient biography or the lifeworld. This approach contrasts conventional biomedical care models. When patients enter conventional biomedical

spaces, the focus on pathology can dislocated illness from experience and patient from their life context. In these conventional biomedical settings, patients often only respond when requests are made of them, give specific information when called for and as demonstrated in this research, may be so disciplined in their obedience to medical authority that they may not even sit down unless invited to do so by their physicians. Physicians in biomedical settings generally hold a great deal of power and authority and exert this power -whether consciously or unconsciously – in the structure of the exchange between physicians and patients. Physicians are bilingual speakers of medical language and their respective conversational language, familiar with both the medical context and life context that surround each human being. Patients, however, generally are not bilingual, speaking and framing their illness experience within their lifeworld. Mishler described a patient's lifeworld as:

> The voice of the lifeworld refers to the patient's contextually-grounded experiences of events and problems in her life. These are reports and descriptions of the world of everyday life expressed from the perspective of a ''natural attitude.'' The timing of events and their significance are dependent on the patient's biographical situation and position in the social world. In contrast, the voice of medicine reflects a technical interest and expresses a ''scientific attitude.'' The meaning of events is provided through abstract rules that serve to decontextualize events, to remove them from particular personal and social contexts (Mishler 1984).

Physicians when treating adults, generally speak in medical and technocratic language while patients often attempt to frame their illness experience and their identity through referencing the lifeworld. The use of the life context by both doctor and patient, however, much like Kleinman's biopsychosocial model, was more characteristic of AM's approach to patient care because of its emphasis on patient biography in treatment (Katon and Kleinman 1981). For individuals like AM patients, the emphasis on the context of the patient with accompanying language to reflect it allowed them to speak and be spoken to in the voice of their lifeworld without censorship, integrating illness experience and causality into their everyday lives and language (Katon and Kleinman 1981). This also contributed to high satisfaction in AM care

(Chamberlin 2017). For AM patients, the use of the lifeworld built trust and satisfaction in AM care particularly since they expected to be included and engaged throughout the consult and treatment process. It gave patients confidence in the quality of care and the intention of the provider who could make recommendations knowing who the patient was more fully rather than who they were written on a medical chart. Patient's referenced how this process empowered them to engage with their own care and gave them the confidence to participate in the process. It was also instrumental in building the therapeutic alliance and cooperation between doctors and patients.

8.2 CONTRASTING CARE AND ONTOLOGIES OF PERSONHOOD

Brazil's nationalized healthcare system has been through several evolutions since democratic reform in 1988, but the promises of a nationalized healthcare system to reduce inequity and encourage democratic participation is still very present in the narratives of Brazilian citizens. SUS physicians expressed a profound sense dedication, meaning and purpose in being able to provide free care and participate in the vision of democratic reform. The narratives of civil responsibility, service and citizenship, were a staple in how physicians described their work. These narratives were also important to how patients' expectations and satisfaction for health care unfolded and impacted healthcare choices. Brazil's democratic reform inserted a specific ontology of personhood through offering universal biomedical care to all citizens to support the transition to a democratic Brazil. Integrative healthcare modalities have since then interjected competing ontologies of personhood.

AM care's injection of a different ontology of personhood into the medical and biopolitical landscape in Brazil did not go unnoticed. One physician was careful to point out the differences he saw in how AM patients approached choice compared to how his SUS patients approached choice. AM patients in his mind, were their own group or "clan" and were looking for "something different." This physician had identified the AM biosociality that set itself apart from his patients through different expectations for care and participation. AM's approach to the human being or their vision of the human being was rooted in the threefold and fourfold view of the person – a spiritual vision of the human being that included what was perceptible and measureable (the physical body) to what was supersensible and/or unmeasurable (the etheric, astral, ego bodies, individual destiny etc.). Patients were not only contextualized by these bodies in the moment but also by their entire biography, network of relationships, and the wider context of the world and its seasons and rhythms surrounding them. All of these elements, and far more than would be cogently included in this research, were woven together with the patient and physician to form a cooperative alliance and an accessible interpretation of illness experience.

The AM view and approach to care is something that AM patients are looking for on some level. How much AM shapes these expectations once patients engage with AM's vision of the human being (produced in medical care through doctors and with patients) and how much patients bring to that initial visit remains to be seen. Certain aspects of the conventional Brazilian biocitizen could be said to exist in the non-conventional Brazilian biocitizen or AM patient. SUS and AM patients both deployed a neoliberal logic of self-care and responsibility but quite differently. These differences impacted the way that AM patients engaged with care and with their providers and their expectations for themselves and for care. It also effected what kinds of care they found satisfactory and dissatisfactory.

AM patients' rejection of a materialist approach was often due to a discomfort or rejection of the doctor patient relationship that had an asymmetrical power imbalance between doctors and patients that ignored life context and framed patient experience in alien medical contexts and language. AM patients believed a certain kind of care was necessary in order to be well and that it was their right to this care and their responsibility to be involved in this care to get well and remain well. In some ways, the narratives around AM and health rights were a reclaiming of the narrative around health and equity that scholars like Birn et. al. have argued were coopted by re-emergent neoliberal policies and actors (2016). SUS and the Brazilian citizenship narratives have fostered the embodiment of proto-neoliberal citizenship by Brazilian biocitizens. This is reflected in the provision of patient rights with an implicit duty to not burden the state. Both AM and SUS patients reference these embodied norms of individual responsibility and rights albeit differently.

Just like biocitizenship endows citizens with inalienable rights based on their status as biological beings, AM practice extends certain rights and responsibilities to patients and doctors based on a threefold/fourfold conception of the human being that encompasses three "bodies" beyond the biological/corporeal one. While a classic conception of biocitizenship would entail patients gaining access to certain health services because of their status as being biologically human amalgamated with their membership in a polity, the rights and responsibilities that come with an AM view of the person differ since its conception of what it means to be human differs. The amalgamation of AM personhood with the Brazilian citizenship open the door for a reinterpretation of the rights and responsibility of biocitizens and their ensuing satisfaction or dissatisfaction with access to resources, services, etc. This is where one is able to see the divide between AM and SUS biomedical practice and why patients begin to choose between the two.

Contrary to popular belief, AM patients do not reject biomedical care as a practice or tool so much as they object to it as a paradigm. Biomedical care is part of AM and a biomedical conception of the physical body is not inconsistent with AM; it is merely seen as incomplete. This was evident in AM patients' rejection of integrative health techniques in SUS that still used a biomedical paradigm. AM patients were generally not looking for different medications so much as they were looking for a different approach to the person and their illness experience that gave them access to different rights and responsibilities. Biomedical care could be and was used by AM patients who trusted their AM physicians to prescribe them as they saw fit. Patient's circumnavigated being subject to the biomedical gaze even when they participated in SUS, however, by routing care through AM physician when they could. The AM physician was then able to reintegrate exams and diagnoses within the patient's life context aligning personhood to illness experience, and the rights and responsibilities of doctors and patients with AM patient expectations.

8.3 IMPLICATIONS FOR PERSONHOOD AND CHOICE

AM patients were similar to their SUS counterparts in many respects even though they made different healthcare choices. They both expressed concerns over medications over side effects and toxicity but AM patients concerns largely stemmed from medicating the symptom rather than the root cause as well as artificially intervening in an illness process that had purpose (lessons about balance, equilibrium, development etc.) with the risk of becoming "dependent" on artificial interventions and medications. SUS and AM patients deployed same idea of responsible self-care but with a different twist. While SUS emphasized not over using the system and being

proactive about using services, and listening to one's doctor, AM patients focused on honesty, doing the work, questioning and knowing oneself.

Not surprisingly different expectations effected what patients were satisfied with and the degree to which they were satisfied with their care. Satisfaction directly effects the second moment in choice – the continuation with a provider. Once the patient has passed through that second moment and choice and has stayed, the vision of the human being and the rights and responsibilities embedded in that care they are choosing can be introduced or solidified in the medical context where doctors and patients produce and reproduce them or negotiate these constructs. While SUS patients generally framed success as having a health issue resolved quickly, AM patients were looking for root cause and someone to help them align illness experience and life context to understand why the illness had occurred. AM patients wanted to be involved in the process or they were generally not satisfied even if the health condition was resolved. Both groups, however, expressed pride in what SUS had set out to accomplish and hoped that it could fully realize its potential.

Overall, AM patients investigated, debated, reflected and worked on themselves integrating medical considerations into many aspects of life and vice versa since AM care made it possible and also encouraged making sense of illness in the life context and being able to be seen contextualized by one's unique life course. Biography and illness, self and rights and responsibilities were both co-created and captured over many visits, written down and through biography work and their paintings etc. Ultimately, AM patients were participating in the promise of the right to health in the 1988 constitution. They took the rights of the conventional Brazilian biocitizen – forged in the joining of democratic agreements between citizens and states and the interpretation of the citizen through nationalized biomedical care - and reinterpreted

those rights and responsibilities of citizenship according to a different view of personhood through AM care. This view of personhood expands the ideal of self from the corporeal to the supersensible, of disease from infection to meaningful life, of illness experience into evolution, and seeking of medical care as an assertion and co-production of personhood and meaning through the inclusion of life context or biographical narrative in the medical consult.

When one SUS physician's asserted that AM patients formed a kind of "clan," he was in a certain sense correct. They formed a biosociality around a different view of the person and his/her ensuring citizenship. This biosociality and medical care reinforced this view whether it was through medical consults, the many courses offered at Sagres, public lectures, musical recitals, the Sagres bookshop or café, eurythmy groups for Waldorf school parents etc. These were spaces where the non-conventional Brazilian biocitizen encountered other non-conventional biocitizens and could share in this vision together. Waldorf schools had the potential to play a supporting role in introducing or solidifying these new norms presented by AM although patients only referenced Waldorf schools as a conduit to finding an AM physician rather than teaching them a different perspective they wished to continue to participate in via AM. These patients' non-conventional biocitizenship is a testament to the power of medicine to shape one's understanding of self, as well as the role of the view of self or personhood in the choice to participate in medicine, what that participation looks like and exactly who the participation is with. Expectations for rights and responsibilities and choice are deeply steeped in this understanding of personhood and how self is allowed and expected to interface or be acknowledged and included in the medical landscape as well as in political institutions.

8.4 IMPLICATIONS FOR MEDICAL CARE

Understanding what drives patients to make medical choices has important implications for developing medical care, deconstructing non-compliance, and expanding PICs into the (conventional) medical landscape. Identifying the mechanisms that underpin choice is important for aligning healthcare approaches and resources in ways that patients will access and continue to do so. This research expands upon previous health care choice models and introduces *additional* catalysts for patient choice to better understand the mechanisms that underpin patient choice. It joins the construction of personhood through a vision of the human being put forth by biomedicine or AM with the vision of the citizen put forth by the state.

SUS is by nature an amalgamation of the state and biomedical care creating conventional Brazilian biocitizens and acting as a boundary object between citizens and the state. What occurs in the relationship between citizens and the state when this boundary object is rejected, remains to be seen. Understanding why patients opt out of this relationship, however, is important especially when it means opting into a different form of care like AM with a contrasting approach to care, philosophy and practice that is informed by a different view of the human being through which it creates non-conventional Brazilian biocitizen with different expectations for their rights and responsibilities in care. This may impact what citizens demand from their State and how these demands evolve over time.

Divergent interpretations of personhood and their ensuring impacts on biocitizenship provide insight into the expectations of patients for themselves and for their medical care. This insight can illuminate an additional reason as to why patients choose care, continue to participate in care, how they mix forms of care and why patients express various forms of satisfaction or cooperation regardless of the technical quality of the care provided. It can provide insight into

how non-compliant patients may in fact view themselves as responsible citizens and patients and why they may view technically exemplary care as unsatisfactory. It also reinvigorates the argument that patient narratives and life worlds have value for physicians and patients in mitigating the power imbalance in the medical setting reducing miscommunication or dissatisfaction on both sides of the doctor patient relationship.

8.5 FUTURE DIRECTIONS FOR THIS RESEARCH

Patient healthcare choice models have historically focused on attempting to explain patient choices through the lens of rationality, hierarchies of resort, and a number of external pressures that overlook individual agency and the production of meaning in healthcare. This research rethinks choice and agency through the lens of personhood and biocitizenship showing how patients are biopolitical actors that gain and assert agency through their selective participation in medical care and biosocialities. It also shows how medical care and biosocialities instill or give structure to resistance and reimagining of ontologies of personhood enabling patients to assert new forms of biocoitizenship, rights seeking and norms around responsibility, entitlement and health behavior. By recapitulating medical pluralism in this way, this research gives new insight into the provision of care, the choice of care, and the meaning made and remade through medical choices that extend far beyond the consultation room.

By reexamining choice in the context of personhood and biocitizenship, this research illustrates the need to examine choice as a reflection of individual agency and meaning making situated in larger contexts of governmentality, medical pluralism, and biopoliticcs. Future directions for this research may lie in exploring how approaches to the person in other modalities

are more or less attractive to patients based on their views of personhood and how these views serve as hubs for fostering alternative ideas about citizenship rights, responsibilities and membership produced and reproduced by medical care and medical participation. This may include reexamining how patients move through pluralistic medical settings by focusing on what ontologies of personhood other modalities produce rather than what treatments they offer as the standard by which patients choose them. Patients can negotiate care directly with doctors in the medical settings or assert their agency outside of this setting in ways that physicians may or may not be aware of. Patients may mix forms of care, resist medication or medical orders precisely because the care does not align with their view of their own personhood and ensuing biocitzienship rather than the assumed lack of healthcare literacy, disinterest in their own health or rejection of biomedical science. Resistance in other words, can be cast as a negotiation or rejection of medical indications and prescriptions especially if negotiation is not explicitly taking place in the consult itself. This research shows the need to not only examine the values contained within medical practice but how these values are tied to greater institutions – like government – that patients may resist through selective participation in medical practice.

Finally, choice and personhood have an important interdependent relationship outside of medical care entirely and provide fruitful grounds to explore their effects on one another in a variety of contexts outside of medical care. The relationship between personhood and choice has a potential to help untangle what may be perceived as the idiosyncrasies of individual choice, connecting individual behaviors to wider entities and practices such as membership and institutions, NGOs and governments.

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